

# Emerging Issues in Impairment and Disability Studies

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EMERGING ISSUES IN IMPAIRMENT  
AND DISABILITY STUDIES

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## INTRODUCTION

The articles included in this book of proceedings were originally presented at the 1987 annual meeting of the Society for Disability Studies (SDS), which met concurrently with the Western Social Science Association, in El Paso, Texas. A variety of approaches to issues in disability studies are represented here, and our goal is to faithfully represent an interdisciplinary orientation.

The theme of this volume is emerging issues in disability studies. To the extent that disability studies is a relatively new field, new issues are constantly emerging and the discipline could hardly be characterized as in a state of "normal science," to borrow a phrase from Thomas Kuhn. Too, since the field of disability studies is interdisciplinary, new issues constantly emerge as researchers synthesize concepts and approaches from various more traditional disciplines (e.g., sociology, political science, psychology, law). Moreover, because of the interdisciplinary nature of disability studies, fresh perspectives emerge on what might be termed "traditional" issues--stigma, attitudes, professional-client relationships, and so forth.

Among some of the key areas of emerging issues included in this volume are: disability and media, disability and sexuality, disability and personal and professional relationships, the institutional processing of persons with disability, disability and social policy, and the relationship between aging and disability. The scope of the articles is broad. Structural forces shaping disability policy are addressed by some of the authors; interactional processes influencing the relationships of persons with disability are addressed by others.

In Chapter I, the roles of the media in shaping public perceptions about



disability are examined. What is revealing is that while the media have power to educate the public about disability, they also have the potential to depict unrealistic and sometimes offensive portrayals of persons with disability.

In Chapter II, a variety of empirical studies on disability are included. The common theme among these articles is public advocacy. How can research be applied in ways that benefit persons with disability in society?

In Chapter III, institutional processing of persons with disability is the focal concern. One article investigates educational institutions, another rehabilitation arrangements for persons who are blind, and a third examines the social history of an institution for mentally handicapped persons.

In Chapter IV, relationships between persons with disability and those who are not disabled are explored. The range of relationships are discussed: how are friendships initiated? What about dating? What sort of salience does disability have in friendships? In sexual relationships?

In Chapter V, disability and economic policy is discussed. The selections represent emerging concerns: the economics of vocational rehabilitation, a critical appraisal of federal prospective payment programs, and similarities and differences between American and British political and economic policies in regard to disability.

Chapter VI deals with the relationship between aging and disability. Older persons represent a growing group with chronic illnesses and disability. Elderly persons with disability pose special issues for professionals, family members, and for the larger society by virtue of their age status, growing numbers, and physical and mental health. The politics of disability apply to older persons with disability as well as with younger ones.

The compendium of works presented here have in common an identification of and concern for emerging issues in disability studies. Many of them avoid



doctrinaire positions on established themes and many others bring to light altogether new issues. As a consequence, these articles truly represent emerging issues in disability studies.



## Chapter I

### Views on Disability in Society Through Media and Literature

Perhaps no other area has received as much attention in professional publications and the popular press as the relationship between media and disability. Despite the attention given to this topic, media and disability remains a fruitful ground for much interdisciplinary research.

Media and literature are communication avenues that profoundly shape public perceptions of disability. These avenues can take the form of public education or the perpetuation of stereotypes. The media and literature can influence the political agenda by bringing to the public attention matters long hidden and ignored (e.g., the play "Children of a Lesser God," the film Best Boy, or, as one author in this volume points out, the crime-mystery novel).

In their presentation, "Disabling Humor," Steve Shindell and Michael Dunn outline for us functions of humor, motives behind cartoon depictions, and how to use humor when working with clients with disability and their families. Shindell and Dunn argue that humor is a legitimated means to reduce anxiety and vent aggression. Persons with disability experience uncomfortable and/or embarrassing situations in the social world. And, from time-to-time, so do those with whom these persons interact. Humor can allow us to address these unscripted social situations in a way that serious discourse does not allow. When humor becomes restrictive (i.e., plays on negative stereotypes), this gives us insight into important attitudes as well. By understanding humor and disability, it is possible to use this medium for individual and family counseling, public education, and gaining important insights into how our communities think and feel about disability and persons with disability.

In "Societal Responses to Two Impairments: AIDS and Leprosy," Ilse Volinn draws parallels and disjunctures between these two diseases, the experiences of

those with AIDS and leprosy, and public responses reflected in the mass media about these two diseases. Volinn notes how media portrayals figure prominently with AIDS and images of leprosy. The notions of stigma, sin, and contamination are central to public images of these two diseases. While medical advances have enhanced treatment of persons with leprosy and legal mandates have reduced discrimination, these avenues are still open questions concerning AIDS.

Irving Zola's witty and insightful, "How is Your Sex Life, Ellery Queen--Portrayal of Disability in the Crime Mystery Genre II," explores the social and emotional lives of major characters with disability in some 200 crime-mystery novels, which represent the data base for this study. If for no other reason, the crime-mystery novel is an important source of data since it is a widely read genre.

Zola observes that the characters with disability in the novels are portrayed in a reasonably positive light, but....The positive depictions involve the fact that these persons with disability work, they take risks, they have sexual relationships, and they can be quite clever at perpetrating or solving crimes, but....The "but" here refers to the lingering stereotypes or the reluctance of authors to deal explicitly with, for example, matters of sexuality.

This paper is the third in a series by Zola on media and disability. We look forward to the next piece in the serial.

In "Media and Disability: The Deaf Detective," Fred Hafferty makes a creative contribution to the line of works initiated by Irving Zola. Examining three deaf detective characters--Drury Lane, Joe Binney, and Sampson Trehune--Hafferty observes that the authors give the reader a "supercrip" crime fighter. This does not help the public misconceptions about persons who are deaf. For

example, Joe Binney is an expert lip reader whose deafness leads him to hone other senses. Sampson Trehune is portrayed in a more realistic light, but Hafferty pointed out elsewhere, Mr. Trehune's first name is no coincidence.

All of the articles in this chapter serve to remind us that the media--their content and form--influence public thinking about disability. To understand this effect is to come closer to shaping media for socially useful (e.g., public education) ends and to combat the socially destructive (e.g., perpetuating negative images) ends.



DISABLING HUMOR: EXAMPLES OF VISUAL MEDIA HUMOR  
DEPICTING PEOPLE WITH DISABILITIES

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The use of humor to disarm, de-fuse, or emotionally deal with stressful events has a long and well established history. Humor is often thought of as an acceptable means to release aggression and anxiety over discomforting topics. Often embarrassing or misunderstood by the public, "crip humor" fills the need of allowing us to laugh at absurd situations such as living with a disability. By critically examining the scores of cartoons collected by the authors it will be possible to detect trends of positive and negative attitudes toward people with disabilities. Similarly, we as clinicians have found humorous cartoons a necessary and integral part of teaching psychological aspects of disability to clients, families, and health care professionals. Examples of such practices will be discussed. During this presentation we will explore the use of humor, identify the target of the aggression or anxiety, and define the underlying message in each cartoon. Audience members will be encouraged to participate both in the discussion as well as the submission of additional slides of appropriate cartoons. The goals of the presentation are to increase the proliferation of humor positively oriented toward people with disabilities while also examining humor that is used as a means of releasing negative aggression toward the disabled population.





## SOCIETAL RESPONSES TO TWO IMPAIRMENTS: AIDS AND LEPROSY

By

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Introduction

Current and projected incidence and prevalence rates relative to AIDS justify the designation of that disease as one of epidemic proportion. The issue is of worldwide significance. A comparison with leprosy, experienced in similar manner about the turn of this century, provides the basis for the analysis of social responses to a life threatening issue.

Methodology

A qualitative methodology was applied. Three broad categories of societal responses were identified and one example from a wealth of possibilities was selected for analysis. The three categories are represented by 1. Individual behaviors and attitudes either expressed by persons themselves or reflected in mass media, 2. Informal institutions characterized by their size and limited power to enforce their collectively formulated decisions, 3. Formal institutions, predominantly represented by governmental agencies. They are large in size, rigorously structured and endowed with powers of enforcement. Decisions are expressed in forms of regulations, policies, ordinances, laws, and congressional acts. Formulated on different levels of hierarchical structures, they tend to be enforced rigorously if a situation is perceived as warranting such an avenue. Domains of power are defined, but tend to overlap. Righteousness of power is disputed. The issue often boils down to the definition, interpretation, and applicability of terminology.

### Congressional Guidelines for AIDS-related Decisions

The Supreme Court decision of March 3, 1987 in the case of School Board of Nassau County, Florida, et al versus Arline represents the basis for this analysis. Implications for the application of the decision to AIDS-related questions already were considered in preliminary arguments discussed by Stephanie Benson Goldberg in the American Bar Association Journal. The comparison of two epidemics, separated by almost a century, highlights a historical perspective necessary for the analysis of society's reaction to epidemics.

### Morbidity Conditions of Leprosy and AIDS

Disease specific characteristics are relevant.

#### Similarities between AIDS and Leprosy

The disease processes are insidious. Since there are long periods without symptoms or only with minor indication of a morbidity condition, ambivalence or total disregard prevails. The incubation period is extensive and can be over 10 years, in the case of leprosy. Since AIDS is a newly discovered disease the maximum length of incubation has not yet been determined. No vaccine is available for AIDS or leprosy. Causative agents have been identified: a virus for AIDS, a bacterium for leprosy. Both diseases are not unified entities, but show variations.

Issues of contagion and modes of transmission are still disputed. The individual's function of the immunity system is a serious consideration. Factors of stigma include many components: notions of "invasion" from foreign lands like Africa, China, Haiti; suspicion of "unacceptable or sinful behavior"; and signs of physical deterioration. Bases for stigmatization have been discussed in great detail by Goffman (1963).

### Differences

The most obvious difference lays in the historical background. Weymouth (1938) contends that archeological relics found in Egypt and dating back to 4000 BC can be used to assume that leprosy had existed at that time.

Historical details are reported by Skinsnes (1973) in great detail.

The microbacterium leprae was identified by Hansen in 1869.

AIDS is a relatively new disease. The virus was identified in 1981. Antibody testing for HTLV III LAV dates from that point in time.

Outcome of the two diseases differs. Although both are chronic, AIDS is lethal while leprosy is curative through drug therapies.

Differential stigma elements are present. AIDS as STD (sexually transmitted disease) is identified with homosexuality, heterosexuality, and drug addiction, behaviors condemned by many sectors of society.

Leprosy, at the present time, is not identified with any "deviant" behavior, as it was in past centuries, when the condition was labeled as "unclean", mysterious, and brought about by sinful conduct.

Currently, in discussions of AIDS, terms like leprosy or lepromatous are frequently used. Sontag's (1977) conceptualization of illness as metaphor can be applied appropriately.

### Society's Response

I selected as an example a specific issue: School Board of Nassau County, Florida et al versus Arline, decided March 3, 1987 by the Supreme Court of the United States. The majority decision was that the School Board had not been justified to dismiss Arline from her position as third grade school teacher. It was a violation of a congressional antidiscrimination provision. The case was remanded to the trial court so that it could give consideration to specific facts as to whether or not Arline was entitled to be considered a handicapped

person on the basis of statutory criteria. Background information: Between 1957 and 1978 Arline had been hospitalized four times with Tuberculosis, a disease which is classified as communicable. The case had moved from the lowest courts to the highest, producing contradictory decisions.

Application of the arguments to AIDS was already discussed prior to the Supreme Court decision. Goldberg, in an article in The American Bar Association Journal (1987), argued that the broad issue is the designation of a condition as handicap. If Tuberculosis and consequently AIDS is classified as handicap, then all communicable diseases fall under provisions of the 1973 Rehabilitation Act, Section 504.

The ambiguity of society's response lays in the differences of definition of the term handicap, and therefore applicability of the provision of the Rehabilitation Act. Sigerist (1943) describes, with a historical perspective, the relationship of social control to life threatening diseases. Leprosy is frequently mentioned in that context. In antiquity, perception of contagiousness created a large number of taboos. In medieval times strict regulations were enforced: isolation, restriction of movements within a community, or in-migration. Sigerist contends that basic differences of kinds and execution of control depend on political structures: authoritarian regimes applying different forms of control than democratic political units. An additional issue is the consideration of a political versus a public health point of view. The contemporary status of medical science also contributes to the formulation of opinions which can be labeled as society's responses.

#### Summary

During the second part of the twentieth century congressional acts and laws have made considerable effort to eliminate various forms of discrimination. The case cited is a demonstration. The majority opinion

expressed the view that all diseases should be classified as handicap unless very strong proves of danger to the public health can be provided. In the case of Florida School Board versus Arline, the Court contends, the medical and public health testimonies were not convincing. The Court intended to protect handicapped individuals from prejudice, stereotypes, and unfounded fear.

In the past, regulations to control communicable diseases referred to apprehension, detention and exclusion from specified places or services. Such measures were officially sanctioned. In the case of leprosy, enforcement has been gradually decreasing since the early 1940's due to advances of medical knowledge and discovery of effective treatment methods. As far as I know, the legality of apprehension and involuntary detention in cases of physical morbidity states has not been challenged until the 1987 Supreme Court decision discussed above.

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HOW'S YOUR SEX LIFE, ELLERY QUEEN?  
THE PORTRAYAL OF DISABILITY IN THE CRIME MYSTERY GENRE

By

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This is the third in a series of papers about the portrayal of disability in the media--all presented here in embryonic form. The first, "Depictions of Disability--Metaphor, Message, and Medium in the Media: A Research and Political Agenda," laid out the dilemmas I was having in trying to understand and ultimately to change our current theoretical conceptions as well as our current portrayals. Like all good academics, I called for more research. Reflecting later on a maxim from my childhood--if you want to do it right, you better do it yourself--I decided to embark on my own series of studies. I chose to focus on an area I thought I'd get the maximum yield from the minimum effort--the crime mystery genre.

My results, like those presented in the previous paper ("Any Distinguishing Features"), are still preliminary, though the data-base has doubled. I have now completed the reading and coding of nearly 200 pieces of crime mystery writing. The present analysis centers on the nature of the social and emotional lives of the characters in such works. Except for characters who appear only as bystanders, there is much available data. We are usually told about their family life and even in the earliest writings, characters with a disability have never been loathe to tell us not only what others think of them but what they think of themselves.

In the most general sense, characters with a disability feel pretty good about themselves and show it. There are, of course, moments of self-pity, self-doubt and even bitterness, but for the most part, such feelings are not

all-pervasive. When they are, the character is most likely to be a 'victim' in a double sense--both of the crime and of their disability. The most vivid example of this is seen in P. D. James' The Black Tower, where one after another, the "pitiable" (in the eyes of the narrator Adam Dagleish) patients of Thornton Grange Sanitorium are being murdered. As mentioned in the previous paper, villains still are often identified by certain kinds of disability, but this does not mean they necessarily feel ashamed of it. The most enduring master criminal of contemporary literature even identifies himself in terms of his disability, The Deaf Man (a recurring character in the Ed McBain 87th Precinct series).

There are two demographics which are at least consistent with this positive self image--their work and their marital status. We may not, for example, always like what they do but the vast majority, with the exception of those who are obviously retired or institutionalized, do work. They may be shamans in the Southwest or homemakers in the Northeast. Some will, of course, be played according to stereotypes--such as people with visual impairments running newsstands. But just as many, if not more, will be over-achievers, often to the bane of their family and lovers. They will be detectives. Interestingly enough, these hero/protagonists (to date, I've met only one female with a disability who fits this role but this, too, is bound to change), while often "hard-boiled", don't seem as likely to be loners. In an earlier era, the era of the gentleman detective, it seemed almost natural that there was someone to assist them for the more physical and routine tasks. Max Carrados and others had their faithful valets; Nero Wolfe his right hand man. The detectives of today do it more subtly. If in the private realm, they are likely to be part of a team. Thus he need not be an armchair detective but a

man back at police headquarters or, as in one case, the fire department, who does investigating rather than patrolling.

Regardless of how they accomplish their task, they nevertheless have chosen a job with more than the usual amount of risk. In earlier times they used their disability as an asset. Those who were blind were supposed to have even sharper survival instincts. Jim Hanvey, once described as the best and fattest detective alive, felt his obesity led informants to trust him and adversaries to underestimate him. Almost all used their disability in at least one positive way. As one put it, without all their faculties, they should, and often did, think twice before leaping into action or to certain conclusions.

Turning to the more intimate aspect of their lives, they, at first glance, seem to do as well, if not better, than most non-fictional counterparts. The nature of the crime mystery genre does not play much to family life. Thus characters with a disability seem to be or have been wed as much as any other character, and much of this marriage and parenting took place after the occurrence of their disability. As for sexual experience, while the issue of disability may be a source of personal doubt in their relationships or having long-term relationships, they do have them. While one-armed Dan Fortune or one-legged Peter Styles may wonder about their ultimate worthiness as a male partner, the problem, as measured by the number of females in ardent pursuit, is clearly more in their own eyes.

I qualify these remarks, however, by saying 'at first glance.' And here an insight of Fred Hafferty is particularly relevant. The reader, in general, is told how sexy or how good a lover someone is but we never actually see it.

Typical is the following third person description in Tom Clancy's Hunt for Red October.

"The loss of his left leg above the knee had not taken away Oliver Wendell Tyler's roguish good looks or his zest for life. His wife could testify to this. Since leaving the active service four years before, they had added three to the two they already had and were working on a sixth."

Now some may argue that this is more a measure of inadequate birth control, but I hope you get my point.

The point becomes even clearer when there is available comparative material. Ed McBain, for example, often dwells on the physical characteristics of his female characters. Thus in one novel, he notes in some detail the major sexual features of the lovers of his 87th Precinct detectives as well as the other women who flow through the pages. The one exception is Teddy, the beautiful deaf and mute sexy wife of Steve Carella; the latter constantly tells us she is a very beautiful and sexy woman but we never know the physical basis on which he makes such an evaluation. A similar omission exists in the actual sexual performance of most characters with a disability, even if they are male. Thus we don't know how Joe Binney manages in the dark when he cannot read lips or whether the loss of an arm alters the foreplay of Dan Fortune or Sid Halley or the missing leg, the position of Peter Styles or Oliver Wendell Tyler or, conversely, how relatively little effect it may have. While other male characters may fondle, caress, penetrate or whatever, when the character has a disability, the sex scenes are only described as happening, not the happening described.

Thus the same reluctance to describe in any specific physical detail an individual's disability (reported in "Any Distinguishing Features") reappears in regard to the physical aspects of their sexuality. Once again there seems to be a line being drawn as to where it is "too close for comfort."

A final finding parallels this. For though there is, as noted previously, no dearth of characters with a disability, except where in a hospital, they have precious little to do with one another. In that sense, they may well have paralleled the reality that existed until the late 1970s. Not only did people with a disability rarely self-identify as such, but when they did, they saw themselves as having little in common with any other people with a disability.



## DISABILITY AND THE MEDIA: THE DEAF DETECTIVE

By

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This paper examines the portrayal of deafness in crime-mystery novels. It is based on a comparative analysis of three deaf detectives, covering a fifty year time period.

The earliest deaf detective examined is Ellery Queen's Drury Lane. Lane is featured in four novels published in the 1930's. Queen's character is a wealthy and retired Shakespearian actor who was forced from the stage because of his increasing, but unexplained deafness. Mr. Lane resides in a castle named The Hamlet which is perched high above the Hudson River and is surrounded by a populated medieval village. Lane is attended to by a host of characters including, Quacey his dwarf hunchback make-up artist, Dromino his chauffeur, and Fallstaff the innkeeper of his Mermaid Tavern.

A more contemporary deaf detective is Jack Livingston's Joe Binney. Joe has now appeared in five detective novels, the first of which was published in 1982, and the first three of which are used in this paper. Binney is a tough, independent, and street wise investigator in the mold of Philip Marlowe and Sam Spade. Joe is a former Navy demolitions expert who lost his hearing as a result of an underwater explosion.

The third deaf detective is Dwight Steward's Sampson Trehune. This character occupies a somewhat middle ground between the urban roughness of Joe Binney and the urbane affluence of Drury Lane. Trehune is a well educated, affluent, and somewhat temperamental book appraiser who lives in Manhattan. He has appeared in one novel published in 1973. Trehune lost his hearing at the



age of nine as a result of a fever.

The basic question guiding this research was what do these books tell us about the nature of being deaf? What view or viewpoint do they represent? Inherent in these questions is the issue of demystification. To what degree do these detective novels bring us in touch with the world of deafness? Conversely, to what extent do they perpetuate myths, stereotypes, or metaphors regarding deafness in particular, or disabilities in general? In this study, a particular emphasis was directed toward analyzing how the reader was expected to know of a character's deafness. What role did deafness play in the plot or story line? Was the reader really introduced to a deaf detective, or to a detective who just happened to be deaf? One finding of this study was that the main character's deafness was often quite incidental to both the development of the plot and the case being solved.

One analytical technique involved recording both the references made to a character's deafness as well as those instances in which a reference might have been expected but was not encountered. For example, a reference to, or a depiction of deafness during a night time scene or in a darkened room would be more expected than a reference made during action in a well lit room or during a direct, face-to-face conversation. Another finding was that missing references were much more prevalent than those actually embedded in the text.

Attention was also devoted to how the references made were actually conveyed to the reader. One of the most important findings of this study was that the depictions of, or references to deafness can be dichotomized into information conveyed in action, versus information conveyed in dialogue. Was the reader told about hearing loss via the words or thoughts of a character, or was the reference embedded in a description of some action sequence? In the former case, the author uses dialogue or flashbacks to tell the reader about

deafness. The disability is thus "explained" to the reader at the same time it is being "explained" to a character in the novel. This technique is a rather direct and fairly unambiguous method for informing the reader about what it means, or is like, to be disabled. This device allows the author to present a great deal of information in a relatively straightforward manner without having to rely on setting or scene.

The alternative strategy is the technique of disability in action. In this case, readers learn about the character's disability as they "see" (as opposed to hear) the consequences or ramifications of being deaf in some detailed sequence involving action. Although the explication of disability via action is somewhat more indirect than through the use of dialogue, it is by its very nature more contextually detailed and situationally rooted. It also allows the author to be more subtle in informing the audience about the nature of the disability. Most importantly, the location of the disability in action requires the reader to directly participate in the interpretive process. The reader is called upon to understand the disability through, and not apart from, the actor. In the eight novels reviewed, the authors were more likely to tell us about deafness than to show us deafness in action.

Deaf detectives were also found to be cast as a "supercrip" (see Zola's "Any Distinguishing Features?" in this issue). This was done in either or both of two ways. First, the character may be portrayed as extraordinary in some social sense. Drury Lane was not only a world famous actor and castle resident, but also a nudist sun worshiper, and, in his first two novels, a superb athlete of fifty who swam two miles every morning in the frigid waters of his lake. Joe Binney, on the other hand, appears plebeian in comparison. Binney smokes too much, gets drunk in the afternoon, and has problems with women only slightly less often than women have problems with him. It is a

mistake, however, to equate the "realism" of a "common person" character with "realism" in the portrayal of deafness. A simple increase in the number of details about deafness, something I refer to as "trait specific characteristics," does not necessarily result in any demystification of deafness. In fact, the sheer amount of "trait factual" detail offered may actually seduce the reader into believing that there is more realism present than meets the ear.

The second type of "supercrip" is an individual whose deafness is a source of compensatory skills, traits, or powers. Deaf people, for example, are supposed to have hypersensitive powers of observation. Both Lane and Binney, for example, rarely misread a lip, misinterpret a conversation, or miss essential dialogue. Although modern day detective novels have moved to portray characters of a more fallible, "everyday," and thus, supposedly, more realistic nature, the mere fact that our hero must work for a living is no guarantee that his disability will render him equally common.

What do these novels tell us about the reality of being deaf? How do they help us "make sense of" what it means to be a deaf person? Through a Joe Binney or a Drury Lane we encounter deaf characters who have "risen above" their deafness. They stand as symbols of triumph over adversity, and perhaps even as folk heroes. The construction of a larger than life, or even a "normally functioning" deaf character, is fraught with commensurate difficulties. Both stand in conflict with any goal of demystification. Deaf detectives such as these contribute to a fundamental distortion of what it means to be deaf. Although separated by half a century, Joe Binney and Drury Lane are deceptively similar deaf characters. Both are supercrips. Binney is actually the more insidious in this respect because, shrouded in his everyman persona, he appears to be the more "realistic." We can easily overlook the

fact that his mistake free, lip reading prowess renders him every much the supercrip as Lane. We can be similarly blinded by the sheer number of trait factual references to Joe's deafness. Finally, the preference by both Queen and Livingston for deafness-through-dialogue tends to obscure the fact that what we are left with in the end is a plethora of knowledge about deafness, but very little knowledge of deafness. Deafness becomes something that the characters have, not something that they are.

Steward's Sampson Trehune, in comparison, fairs much better, Trehune is a survivor, but with scars. In his introduction, Steward notes that most of the dialogue in this book, although told from the perspective of a deaf person, has been normalized. He does, however, grace us with enough examples of broken sentences, false starts and stops, and partially seen and thus partially understood conversations to both enlighten and educate his readers. It is with Sampson Trehune that we are reminded of why deafness is a disability and not "simply" a physical impairment.



## Chapter II

### Empirical Research on Disability

Empirical research on disability represents an emerging theme in several important ways. First, to the extent that disability studies as a field of inquiry is relatively new, there is not an established body of research literature on disability. There are government agency statistics and so forth to be sure, but the systematic analysis of data on disability is a recent, welcomed trend. Disability research is particularly important in that it can inform the development of social policy.

Second, the topics of inquiry in disability studies research are growing as well. The three selections in this chapter illustrate the range of subjects that investigators are exploring in contemporary research.

In "Consumerist Attitudes and Communication of Muscular Dystrophy Patients Interacting with Physicians," Analee Beisecker employs a decidedly applied approach to her social research. She interviewed 106 persons diagnosed with muscular dystrophy. The focus of the research was medical consumerism. Patients with muscular dystrophy face a unique situation: there is no cure for muscular dystrophy but they must seek assistance from physicians who are not always supportive when patients pursue self-treatment. Patients were not altogether satisfied with physicians' responses to questions, such as "what about having children?" (M.S. is a genetically-transmitted disorder).

In "The Effect of Congenital Disability on Sexuality," Elaine Makas focuses on the need for sex education among persons with congenital disability. Makas points out that there are few sex education resources available for persons with disability, and this paucity of resources is due in part to various rehabilitation workers feeling it is not their responsibility to educate clients in sexuality issues. Moreover, because of the range of

disabilities found in any community, the method of communicating sex education information, must be varied. For example, a person who is developmentally disabled will require different communication methods compared to a person who is blind or a person with spinal-cord injury.

In "Morbidity and Morality After Polio: The Development of the Pittsburgh Registry," Jonathan Ramlow, Ronald LaPorte, and Caroline Kaufman discuss the development of a data base in Pittsburgh that includes persons who contracted poliomyelitis. This data base is important since we do not know the long-term effects of poliomyelitis; it is only recently that "post-polio syndrome" has been identified and researched medically. The registry represents a systematic approach to gathering social and medical data that before had remained anecdotal. Consequently, little serious attention was given, until recently, to post-polio patients describing neuromuscular symptoms.



CONSUMERIST ATTITUDES AND COMMUNICATION OF MUSCULAR DYSTROPHY  
PATIENTS INTERACTING WITH PHYSICIANS

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To examine attitudes and behaviors reflecting medical consumerism, we observed and tape-recorded the interactions of rehabilitation medicine outpatients with their doctors. Each patient completed a demographic questionnaire, was tape-recorded during his or her entire doctor's appointment, and participated in a post-appointment interview. After a two-week delay, each patient completed an opinion survey assessing attitudes toward medical consumerism: willingness to challenge physician authority, belief in rights to medical information, belief in rights to medical decision-making, locus of authority in decision-making and desire for medical information. The tape-recordings were analyzed for evidence of patient consumerist communication behavior including information-seeking attempts, assertive comments, and suggestions for treatments other than those proposed by the doctor.

Of the 106 patients for which we had complete data, 33 had a primary diagnosis of muscular dystrophy. These 33 patients ranged in age from 17-80 with a mean age of 40.03 years. Muscular dystrophy patients were seen by physiatrists in a weekly clinic sponsored by the Muscular Dystrophy Association.

Muscular dystrophy refers to a group of diseases marked by wasting and progressive weakness of the skeletal muscles, those muscles that control body movement. At the present time there is no cure and no way to arrest the progress of the disease. Muscular dystrophy is inherited and is not

contagious. Almost 2/3 of muscular dystrophy cases are children, but some forms develop in the teens, twenties or even middle age. .

Although children are disproportionately afflicted with muscular dystrophy, we excluded all patients under 16 years of age because we wished to study the interaction of patients with doctors, and we felt that children under sixteen would defer to their parents and therefore would not ask questions or overtly disagree with physicians during medical encounters.

Multiple regression analyses indicated that the muscular dystrophy diagnosis was a significant factor in explaining patient consumerist comments. The correlation coefficient for muscular dystrophy with consumerist comments was .31 ( $p < .001$ ), indicating that patients with muscular dystrophy tended to make more consumerist comments to their doctors than did patients without this diagnosis. Five of the six patients making 17 or more consumerist comments during the medical encounter had muscular dystrophy. Throughout the course of their illness, muscular dystrophy patients gain considerable experience in the health care system and are often frustrated as their condition deteriorates. Therefore, it is not surprising that these experienced, frustrated patients asked more questions and made more consumerist comments to physicians.

Muscular dystrophy patients are particularly frustrated with the medical system since doctors have been unable to find a cure while, at the same time, Jerry Lewis tells them that a cure is very close. Jerry's message and their own doctor's comments are often contradictory. Many patients return to the muscular dystrophy clinic, not because they expect anything from the doctors, but because they want to be sure their name is still on the list when a cure is found.

Several patients expressed frustration, noting that doctors were not treating them aggressively and that physicians had a negative attitude toward

the patients' attempts at self-treatment. Some patients refuse to use needed assistive devices such as braces. They feel a cure may be so close that they don't want their remaining muscle strength to atrophy by reliance on supportive devices. As a result, they take risks of falling and overtaxing what muscle strength they still retain. One patient noted that using assistive devices was like admitting you're giving in to the disease.

Other patients relied on nutritional treatments not advocated by their physicians. Patients discussed these noncompliant strategies with the investigator, but had never mentioned them, or their reasons for utilizing them, to their physicians.

During the post-interaction interview, we asked patients whether or not they wanted input in medical decision-making regarding their own care. Of the 29 muscular dystrophy patients responding, 24 wanted input in medical decision-making, one didn't care about making decisions but wanted to know what was going on, and only four patients did not want input. The percentage of muscular dystrophy patients wanting input in medical decision-making (82.76) was larger than the percentage of rehabilitation medicine patients in general desiring such input (75.5%). Of the four muscular dystrophy patients not desiring input in making medical decisions, three were 80 years of age and the fourth was an 18-year-old who had "never thought about it."

Since muscular dystrophy has a genetic basis, one area of decision-making and discussion with physicians concerns child bearing. One patient and her fiancé indicated that they wished to have children and asked for the doctor's blessing. The doctor explained the risks involved, both in possibly passing the disease to offspring and physical risks to the mother who is wheelchair bound. A year later, it was obvious that they had ignored the physician's

advice, had borne a child, and the mother had experienced medical crises during pregnancy and delivery.

In contrast to the couple described above who desired to have children despite the risks, another couple expressed their frustration because they found such risks unacceptable.

But when you walk with the disease, you fear. At least we know that I got this one and I could pass it on. And that's stronger odds than someone without. They're not that good, see.

The most frequently mentioned characteristic of an ideal doctor was the ability to exhibit concern, interest and compassion. Patients also wanted a doctor who was truthful, competent, friendly, a good listener who gave matter-of-fact explanations and took enough time with them, characteristics most people desire in a doctor. In addition, some wanted a doctor who was willing to try anything and would not put the patient down for his beliefs. Perhaps because muscular dystrophy patients do make suggestions to their physicians regarding possible "cures" or treatments, they are more frequently "put down" by their physicians. One mother and her son thought an ideal doctor should be open-minded and willing to try new things, because "if there's no hope, there's nothing."

The common theme running through the interviews is that of frustration. One major source of that frustration is the patients' perceptions that doctors don't seem to be getting anyplace in treating individual patients and are unsupportive of the patients' attempts to innovate and treat themselves. At the same time Jerry Lewis is publicly announcing that we are very close to a cure for muscular dystrophy.

The public statements made by Jerry Lewis in an attempt to raise money for worthwhile research, may be dysfunctional for the patients he is trying to

help. These are the people who most want to believe Jerry; their lives and lifestyles are at stake. However, they see no improvement or "cure" in their own medical cases. This discrepancy leads them to believe that their doctor is not on the cutting edge of research, is not innovative and is not a risk-taker. If your own life is at stake, you're willing to be a risk-taker when you see no progress being made with traditional, conservative treatments.

The muscular dystrophy telethon has heightened public interest in finding a cure for these dreaded diseases. At the same time it has raised the level of aspiration for muscular dystrophy patients. When their aspirations cannot be fulfilled, they vent their frustrations on their physicians. These unfulfilled aspirations with accompanying frustrations for the patient are potentially damaging to a successful doctor-patient relationship.



## THE EFFECT OF CONGENITAL DISABILITY ON SEXUALITY

By

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Despite recent research interest in sexuality and disability, one area remains relatively uninvestigated: the need for sex education/counseling resources for people with congenital disabilities that do not have obvious physical impact on sexual activity. It is this overlooked area which I would like to address.

Much of the material I will be presenting is based on a re-examination of data collected by the Sex & Disability Project at The George Washington University during 1978 and 1979. (See Who Cares? A Handbook on Sex Education and Counseling Services for Disabled People by Cornelius, Chipouras, Makas, & Daniels, 1982.) The goal of the Sex & Disability Project was to identify the need for and the availability of sexuality-related resources in disability-related settings (e.g., rehabilitation centers) and the need for and the availability of disability-related resources in sexuality-related settings (e.g., family planning clinics). The study involved an extensive review of existing information and the administration of surveys to disabled individuals (n=97), state vocational rehabilitation counselors (n=156), community service providers (n=45), rehabilitation trainers (n=19), and rehabilitation administrators (n=13). We found a great deal of expressed need among disabled respondents for sex education/counseling information, very few sexuality-related services or resources for people with disabilities, and a wide array of rationalizations among rehabilitation professionals and community service providers for this large gap between expressed need and availability.



Our research suggested a number of specific needs that people with early onset and/or non-mobility impairing disabilities might have. Time permits me to focus on only one: the need for general sex education information (i.e., information not specific to disability). This need was expressed twice as frequently by subjects disabled before age 11 as by those disabled later in life. This may be due to any of a number of factors: 1) people who had been special education students may have been less likely than other students to have received sex education in school; 2) individuals with early onset disabilities may have spent more time with adults and less time with their peers than individuals who, as children or adolescents, had been nondisabled; 3) people who had been disabled at an early age may have been treated as being more child-like than their nondisabled peers, thus excluding "adult" topics, such as sexuality, from parent-child discussions; 4) persons with early onset disabilities may not have been considered part of in-group conversations among adolescent peers during which information on sexuality was relayed (e.g., through "dirty" jokes, hearsay "wisdom," or sexually-explicit magazines and books). Those disabled at a later age certainly may encounter many obstacles to their full expression of sexuality; however, they would have had the same opportunity as nondisabled individuals to learn the basic "facts of life."

The need for general sex education information may be particularly acute for people who have had communication-impairing disabilities since their early years. One means of acquiring sexual information is through reading. However, most written materials on sexuality are linguistically complex. Although a few publications (e.g., Gordon, 1975; Varner & Freeman, 1976) utilize a simplified format, the majority are inaccessible to people with mental retardation or severe dyslexia, or to some people with hearing impairments for whom English is a second language (with sign language being the first). In addition, it is



rare for sex-related information to be put on tape for people with visual impairments or dyslexia.

Sexual information is also acquired through listening (e.g., to sex-related jokes, to sexually-informative movie or TV soundtracks, or to actual or fantasized accounts of sexual experiences). Since much of this information is transmitted in whispers, frequently behind one's hand, a person with limited hearing or with auditory processing problems will have difficulty acquiring this important information. A further problem for a person who uses sign language is that those in a position to give accurate sex-related information may not know sexually-explicit signs. Two recent dictionaries of signs associated with sex (Doughten, Minkin, & Rosen, 1978; Woodward, 1978) are important steps toward alleviating this latter communication problem. The young person, however, due to other access difficulties, may not even have enough information to ask relevant questions.

Observation is another means for acquiring sexual information. Sexually-explicit pictures in magazines and books, though important sources of adolescent enlightenment, are rarely available to a visually-impaired person or to someone with severe visual processing problems. Important information is also gained through observation of others' bodies, both clothed and unclothed. Since social custom prohibits tactile exploration of others' bodies and, to some extent, tactile exploration of one's own body, a person who has been visually impaired since an early age may be more naive about sex differences than his/her peers. A number of educational materials have been developed to alleviate these problems of visual access to sexual information: sexually-explicit anatomical models which may be tactually explored (e.g., Jackson, undated); audiotapes (e.g., "Your Changing Body: A Guided Self Exploration" by

Allen & Lipke, 1974); raised-line drawings (e.g., Dodge, 1979; and thick-lined drawings (e.g., the Boston Women's Health Book Collective, 1976).

Analyses to date of disabled consumers' responses to the Sex & Disability Project survey (Cornelius et al., 1982) found that respondents with communication-related disabilities indicated a greater need for general sex education information (27%), while those with spinal cord injury expressed a much greater need for sex and disability-specific information (57%) than for general information on sex (10%). It was also found that respondents with communication impairments had received very few sexuality-related services of any type, compared to those with spinal cord injuries. One possible explanation is that service providers may erroneously assume that disabilities which do not have a direct physical impact on sexual functioning will not interfere with a person's full sexual expression.

The Sex & Disability Project surveys found that, although 19% of all disabled respondents (and 27% of the communication-impaired respondents) indicated that they would use a general sex education course if one were available, only 2% of the rehabilitation counselors and 7% of the community service providers indicated that they had ever provided this service to disabled clients. The low priority of this service from a professional perspective can be seen clearly in the responses of rehabilitation policy makers. Although the policy makers indicated that they felt rehabilitation counselors should provide some sexuality-related services, none considered general sex education to be a counselor's responsibility.

One of the most disturbing findings of the Sex & Disability Project is that many of the professionals whom the disabled respondents felt should provide sex education/counseling indicated that it was someone else's job. 31% of the disabled respondents suggested that rehabilitation counselors should

provide at least some of these services. Although 58% of the rehabilitation counselors agreed that they should be providing these services, most (72%) indicated that they had never done so; and the majority of those who had provided services had restricted themselves to social skills training and individual counseling. The counselors reported many referrals for all services, and, in all but a few cases, they indicated that these referrals had been made to someone outside of the agency.

Community service providers, however, also appeared to be unwilling to address the sex education/counseling needs of disabled people. Disabled respondents indicated that community service providers should be able to help them with sexuality-related questions or concerns (e.g., 64% indicated that physicians should be available as resources for these services, 51% indicated psychologists, and 25% indicated social workers). These service providers, however, were as likely to describe their role to be the referral of disabled people with sex-related concerns to other professionals (45%) as they were to describe it to be the provision of these services themselves (45%). As a matter of fact, only 15% of all community service providers surveyed indicated that they or their organizations should be the primary providers of sex-related services to disabled persons. Our research suggests that this reluctance to deal with the sex education/counseling needs of disabled people may be even greater for those whose needs are not even recognized or understood. The solution to the problem is not to detract from the needs of people with mobility-restricting and/or traumatic disabilities; rather, the solution is to work together to emphasize the rights of all people to accessible sex education/counseling services.

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MORBIDITY AND MORTALITY AFTER POLIO.  
THE DEVELOPMENT OF THE PITTSBURGH POLIO REGISTRY

By

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There exists throughout the U.S. a population of approximately 500,000 persons who contracted poliomyelitis at some time in the past; many of these persons are disabled, with concomitant limitations of activity. Little is known about long-term morbidity and mortality in these polio survivors. The Pittsburgh Polio Registry was developed because of recently renewed interest in the natural history of poliomyelitis and polio-related impairments and disability.

Previously, the physical impairments and disability resulting from acute polio were generally considered to be stable and non-progressive. The estimated 300,000 Americans living with the residual effects of paralytic polio were not thought to be at risk for further neuromuscular deterioration once they had achieved their maximum levels of rehabilitation 10 years after the original illness (on the average). This view has had to be changed due to the appearance of a late-onset syndrome of new neuromuscular changes in an increasing number of polio survivors. This condition, consisting clinically of new weakness and pain in muscles which were either affected or unaffected by the original acute illness, has been labeled the "post-polio syndrome" or "post-polio muscular weakness" by some clinicians. The syndrome tends to appear rather consistently at about 30-40 years post-infection. In addition to new muscle weakness and pain, many post-polio patients report severe fatigue and decreased functional endurance. This syndrome can result in significant



functional deterioration but does not appear to be rapidly progressive or life-threatening.

The cause of this syndrome is still uncertain, although it is not due to a recurrence of acute polio nor to reactivation of a latent poliovirus infection. It is likely that age-dependent loss of anterior horn cells from an already compromised motor neuron pool is the proximal cause of weakness, pain, and fatigue, but the underlying etiology of this loss remains to be determined.

The goals of post-polio research at the University of Pittsburgh are as follows:

- 1) to assemble a population-based registry of polio cases identified from original medical or hospital records, so that the diagnosis of poliomyelitis and the severity of the acute illness could be verified;
- 2) to locate as many as possible of the eligible cases for determination of current vital status;
- 3) to conduct a valid survey of the traceable cohort members to estimate the prevalence of the post-polio syndrome and other late effects of polio;
- 4) to conduct analytic studies to identify those factors, personal, clinical, or environmental, which might predict risk of polio late effects.

Over 50% of all polio cases occurring in Allegheny County, Pennsylvania, were treated in the municipal Hospital of Pittsburgh (a communicable disease isolation hospital closed in 1956). The records from this hospital, and a small number from the Children's Hospital of Pittsburgh, were the primary source for the registry. Records review resulted in the registration of 1620 cases diagnosed between January 1, 1950 and December 31, 1955. Cross-checking against communicable disease reporting logs held by the Allegheny County Health Department showed that 95% ascertainment of the reported case total was achieved.

Cases eligible for follow-up tracing were:

- 1) residents of Allegheny County at the time of the acute illness;
- 2) found to have a verified diagnosis of poliomyelitis;
- 3) discharged alive after the acute illness.

Of the 828 eligible cases, 458 are males and 370 are females. Nearly all, 95%, are Caucasian. Their average age at onset was 8.7 years, with 83% of the cases under age 16 at onset. Current average age of the cohort members is 43.8 years, with a range of 33 to 82 years.

Of the 828 eligible cases, 63% had the spinal form of paralytic polio (weakness in one or more limbs, chest, back, or abdominal muscles). Twelve percent had the bulbar form of polio (weakness of facial, palatal, or pharyngeal muscles). Another 10% had bulbar-spinal polio (bulbar symptoms plus paralysis in one or more limbs). Finally, 15% of the cases had nonparalytic polio (characteristic symptoms of central nervous system infection, but no detectable bulbar or spinal weakness).

By definition, all cases of nonparalytic polio were classified as mild. There was an increasing trend of severity from the spinal cases (32% mild, 46% moderate, 22% severe) to the bulbar cases (21% mild, 66% moderate, 13% severe) to the bulbospinal cases (8% mild, 40% moderate, 52% severe). During the acute illness 17.6% of the paralytic cases had any respiratory involvement (by the early 1950's respiratory polio fatality was reduced to under 3% of the total).

Approximately 60% of the 828 eligible cases have been traced for follow-up ascertainment using local direct and reverse telephone directories to contact the cases themselves, family members, or neighbors. Another 20% should be traceable using motor vehicle records, voter registration information, and high school reunion lists. The remaining 20% will be difficult to locate because the cases are women whose last names have changed, are members of families who



left the Pittsburgh area many years ago leaving no relatives or friends behind, or are estranged from their families in one way or another.

To evaluate the occurrence of late effects of polio in this incidence cohort, a questionnaire was designed and validated in a small clinical sample. Forty cohort members attending a free post-polio research clinic completed the questionnaire and were interviewed blindly by the study physician (MAA). The questionnaire asked about specific symptoms (pain, weakness, fatigue, cramp, breathing difficulty), changes in functional abilities, use of assistive devices, and history of major medical conditions. The interviewing physician focused on reported symptoms and functional changes indicative of new muscle weakness, in support of a classification of "probably post-polio syndrome." The questionnaire responses were compared with the physician's evaluations in order to arrive at an estimate of the questionnaire's validity. With a small number of revisions, the questionnaire should have good sensitivity and specificity in the general cohort survey, which is currently being carried out.

The significance of this project lies in its epidemiologic scope. Much of the previous work in the area of the natural history of polio took the form of clinical studies or small, unrepresentative population studies. The Pittsburgh Polio registry cohort arose from a defined population (Allegheny County, PA) and is a complete incidence cohort of polio cases with well-documented and verified diagnoses. Because this population represents the entire clinical spectrum of acute polio, it will be possible to estimate the true incidence of polio late effects in all cases of any severity. In addition, further analytical studies will be able to identify the determinants of polio late effects. This information may be useful in the prevention of late effects among the thousands of persons who continue to contract polio in other parts of the world.

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### Chapter III

#### Disability, Politics and Labeling

In recent years, sociologists, psychologists and anthropologists concerned with disability have become increasingly interested in the complex relationship between politics and labeling. More precisely, social scientists concerned with disability have come to realize that in order to understand fully the position of disabled people in society, it is necessary to grasp the social and political forces that shape the process socially defining disability and labeling persons with disabilities.

We begin our discussion of this relationship with the suggestion that groups in positions of power are able to shape culture and the basic institutions of society in their image. (The types of groups we are referring to may include able-bodied people in a world where being able-bodied is the norm.) Their aspirations and definitions of what is valued, in general, shape the basic institutional forms of society. Their definition of disabling conditions and disabled people, in particular, become the accepted definitions of society. The means by which all this occurs is, first and foremost, a social and political process involving significant power differences among various groups in society.

In regard to disability, the significance of the process by which the basic institutions of society are shaped becomes clear when considering two major people-shaping institutions of society: schools and rehabilitation agencies. Agents of both institutions are viewed as having special knowledge and skills; the institutions are perceived by the public as credible sources of instruction. They are both charged with imparting special knowledge and bringing about some sort of change in the behavior of their clients.

The above discussion suggests, however, that these institutions, in the

final analysis, reflect the interests of members of the dominant culture in a culturally varied society. Persons or groups who vary from the norms of the institutions or who are bearers of a condition defined as problematic by the institution, may find themselves devalued and subject to negative stereotypes and labels, which themselves may have disabling consequences. The three articles included in this chapter reflect the growing concern about the relationship between social and political forces and the labeling of persons with disabilities.

In "The Labelling Process and Its Long-Term Educational, Social, and Economic Impacts on Black Children," Helal Mobasher and Steve Barnett empirically assess alternative explanations of the labelling process (the clinical perspective as versus the sociological and social-psychological perspectives) as they apply to low-income black children and the "mentally retarded" label in the public schools. Mobasher and Barnett (1987) focus on "the predictions of [the] alternative theories with respect to: (a) the characteristics that result in a child receiving the label of educable mental retardation (EMR), and (b) the educational, social, and economic consequences of the label." The data for this study were derived from a 20-year study of the effects of preschool intervention and include educational records and questionnaire responses from parents and children.

In regard to the characteristics that result in the child receiving the EMR label, a wide variety of variables in addition to IQ were found to influence the assignment of the "mentally retarded" label to black children. These factors include preschool intervention, the numbers of older siblings, antisocial behavior, and whether the mother is employed outside the home.

The above factors were also found to have significant effects on IQ. The IQ levels of black students were found to be significantly influenced by



socioeconomic status, preschool intervention at age five only and, surprisingly, EMR placement.

In regard to the consequences of being labelled mentally retarded, the EMR label does not appear to influence the "long-range social adjustment outside of school except as this might be inferred from the APL (adult performance level) which is a test of social adaptation" (Mobasher and Barnett, 1987). Mobasher and Barnett (1987) conclude by suggesting that their findings "support some social models of labelling over the clinical model."

In "Blindness Rehabilitation Agencies and Organizational Environment: A Test of the Population-Ecology Model," Stephanie L. Shanks-Meile employs quantitative research methods to test the findings of Robert Scott (1969) in The Making of Blind Men. A major goal of this study is to assess systematically the effects of interorganizational competition for clients among agencies serving severely visually impaired persons. Scott (1969) had suggested that competition for clients would make rehabilitation agencies reluctant to release their charges.

The data for this study were derived from the responses to a questionnaire mailed to 446 agencies serving the visually impaired. Questionnaires were solicited from agencies in areas with both high and low levels of environmental competition.

The major finding of the study suggests that increased competition leads to greater retention of clients. Increased competition was also found to have little or not impact on organizational size and structure.

Finally, in "The Creation of Chronicity: An Institutional Case Study of Social Policy and Severe Retardation in the Progressive Era," Philip M. Ferguson, in an extremely interesting and thought provoking historical case study, explores the means by which original institutional mandates are often

redefined with time and contact with the broader set of social forces within which institutions evolve. The case in point is the Rome State Custodial Asylum for Unteachable Idiots that was established in 1894 and charged with serving the most severely limited part of the retarded population. The original focus, however, lasted only eight years and began to be redefined in 1902 under the administration of the Institutions second superintendent, Charles Bernstein. From this point forward, Rome increasingly came to serve a mildly retarded population.

Ferguson identifies in particular two insights of value for understanding the debates and issues of the current day pertaining to disability suggested by the Rome case study. First, the beginnings of professionalism insured the eventual identification of a population in need of services. "No move to professional respectability can base itself on a simple model of custodial housekeeping" (Ferguson, 1987). Second, Ferguson points out that the Rome reforms were largely based on the contention that mildly retarded persons could be made useful and productive and therefore deserved to be accepted back into society. The reliance on economic productivity as the single standard of success, however, doomed this approach to reform. The history of the Rome Asylum suggests "that any reform that accepts the imposition of economic utility as the price of social integration may condemn itself to ... episodic and partial success." Modern capitalism largely defines the value of people in terms of what their labor will command in the marketplace. Unfortunately, the logic of the marketplace requires the failure of many at the price of the success of a few. This tendency works to the clear disadvantage of the least skilled and most vulnerable segments of the work force, such as mentally retarded people.



THE LABELLING PROCESS AND ITS LONG-TERM EDUCATIONAL,  
SOCIAL, AND ECONOMIC IMPACTS ON BLACK CHILDREN

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Labelling is a process of classification in which an individual or a group of individuals are designated as deviant. The labelling process involves a transaction between the presumed or real characteristics of a child, on the one hand, and the evaluational system of a social institution such as a school, on the other. Thus, on the basis of some combination of a child's physical, cognitive, social emotional, and behavioral characteristics, school personnel may apply the label "mental retardation" (Dokecki 1978, p. 247). Theoretical explanations of what "normal" means range from the predominant clinical model on one end of the continuum to the social system and sociological models on the other.

From the clinical perspective, mental retardation is a handicapping condition that exists in the individual and can only be detected by trained professionals using properly standardized assessment techniques. The clinical perspective uses pathological and statistical models to explain deviance. In the pathological model, normal is equated with the absence of pathological symptoms, while the presence of such symptoms is considered abnormal. In contrast, the statistical model defines abnormality by the extent to which the individual differs from the population average on a particular trait. Conventionally, the mean is the norm and scores with slight variations from the mean are considered to fall in the normal range. In statistical model, normal intelligence is equated with the mean plus or minus two standard deviations.

The sociological and social psychological perspectives of mental retardation differ sharply from the clinical and psychological models. Labelling in general, and mental retardation in particular, are viewed as social phenomena. In these models, mental retardation is an acquired social status and is compared with other social statuses. The person holding a social position is expected to perform certain roles. Behavior is normal as long as it conforms to the norms and expectations of a given system, and abnormal if it significantly deviates from those norms and expectations. Consequently, an abnormal behavior in one social setting may be considered normal in another setting.

The social perspectives maintain that labelling is associated with differential treatment and expectations which exclude the labelled individual from normal social life. Through interaction with others the labelled individual internalizes the deviant label (Becker, 1963, 1974, Goffman 1964). In their study of Black young adults, Koegel and Edgerton (1982) found that a significant portion of the subjects who were labelled mentally retarded perceived themselves as handicapped.

Research on the long-term effects of labelling a child "mentally retarded" has been extensive, yet inconclusive (MacMillan et al., 1974). Cobb (1972), Gruenburg (1964), MacMillan (1977), suggest that many graduates of EMR classes are absorbed into the general population after they leave school, although little is known about the overall quality of lives of EMR black students (Koegel and Edgerton, 1982). Rowitz (1974) has reviewed the research on the epidemiology of mental retardation and summarized the following findings: a) among the mildly retarded, children from low income families and minority groups are over represented; b) the likelihood of being labelled retarded is higher for the children with behavior problems; c) male children are more

likely to be labelled retarded; d) the primary labelling agent for mildly retarded children is school.

### Factors Affecting Special Education Placement

As indicated above, a disproportionate number of students in special education programs are from minority groups and from socioeconomic levels. According to Rivers (1973) and others, Black children are more likely to be labelled "educable mentally retarded" and placed in special education programs than White children. A factor correlated race that also affects special education placement is socioeconomic status. Other determinants of special education placement are preschool intervention, mother's work experience, and number of children.

### Research Design

This paper presents an empirical investigation of Black children from low-income families and the label of mental retardation in public school. The data for this study derive from a 20-year study of the effects of preschool intervention (Schweinhart & Weikart, 1980). Educational records and questionnaire responses of parents and children are used to test the predictions of alternative theories with respect to: (a) the characteristics that result in a child receiving the label of educable mental retardation (EMR), and (b) the educational, social, and economic consequences of the label.

### Findings

Contrary to the conventional argument that IQ is the sole determinant of the EMR label, our analyses show that other factors are equally important. Preschool intervention, number of older siblings, antisocial behavior, and

whether a child's mother is employed outside the home were found to significantly affect the probability of an EMR label. Separate analysis for boys and girls found significant effects of antisocial behavior and older siblings on EMR labelling for boys only.

The same battery of variables are employed to estimate their effects on IQ at age 5, 7, 10, and 15. SES shows significant and consistent effects on IQs through all four different ages. Those from higher SES families are likely to have higher IQs than those from lower SES families. Preschool intervention has a substantial effect on IQ only at age 5. There is also a significant effect of EMR placement on IQ at ages 7, 10, and 15 suggesting that labelling a child mentally retarded at an early age negatively affects a child's later IQ.

Further analyses indicate that being labelled EMR does not effect long range social adjustment outside of school except as this might be inferred from the APL (adult performance level) which is a test of social adaptation. There is no evidence that those who were labelled mentally retarded perform more poorly in real life as we found no significant effects on measures of social adjustment such as: being self-supporting at age 19, work satisfaction, employment at age 19. Analyses of the influence of early IQ (age 5) show the same patterns, except that early IQ is related to affective development and post-secondary education.

### Discussion

Our findings suggest that factors other than IQ are crucial for explaining labelling, at least for minority groups. Among these factors are "antisocial" behavior and SES. These findings support some social models of labelling over the clinical model. According to clinical model, children who are mentally retarded, (determined by IQ and adaptive behavior), will do poorly in later

life. Our analysis indicates that this is not necessarily true. Although IQ affects achievement test scores and affective development, we found no significant effects on other life outcomes.

Some labelling models maintain that labelling a child EMR has lasting effects on life outcomes. Other labelling models disagree. They claim that labelling is a process of classification in school and has little effect on later life, an argument supported by our findings.

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BLINDNESS REHABILITATION AGENCIES AND ORGANIZATIONAL ENVIRONMENTS:  
A TEST OF THE POPULATION-ECOLOGY MODEL

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While the phenomenon of "blindness" for the individual has been examined at great length through past research in medicine, education, and the behavioral sciences, the organization of the blindness rehabilitation system and its impact on client outcomes has been largely ignored. Scott, in The Making of Blind Men (1969), found that blindness agencies socialize people into "the blind role" which is one of dependence and subordination without any differentiation according to the level of functional vision. The level of functional vision is not the primary cause of "failure" in reaching the goal of rehabilitation, rather it is the agency itself which promotes the production of individuals who cannot be integrated effectively into society. Scott (pp. 97-101) also examined the relationship between the size of "the blind" population and the number of agencies in large metropolitan areas on the East Coast. He concluded from his secondary data source that most urban areas have a small proportion of the population classified in "the blind" category, but a wide variety and large number of services are available to those few clients in that community. This disparity leads to an extremely competitive system in which agencies actively struggle over limited clientele. Rehabilitation facilities become reluctant to release present clientele, because it becomes difficult to locate a suitable replacement given that agencies are designed to meet the needs of a specific type of "blind" person which excludes a large portion of "the blind" population. When competition over clientele stiffens, rehabilitation agencies may delay a client's re-entry to the community to meet



the needs of the organization by continuing to rehabilitate those persons until more clientele can be located and entered into the program.

Since Scott's (1969) appraisal of blindness rehabilitation was limited to the use of secondary data in only three metropolitan areas, this study was designed to more systematically examine interorganizational competition. The population-ecology model was selected as a theoretical representation of Scott's earlier findings. This model suggests that inter-organizational competition over clientele leads to adaptations within the organizational structure which will, in turn, affect the processing of clientele just as biological organisms must evolve to survive in dynamic environments.

Data were gathered from agencies in states with high and low levels of environmental competition. Environmental competition was determined by calculating ratios of the number of legally blind persons in each state (National Society to Prevent Blindness, 1980) divided by the number of agencies listed for each state in the American Foundation for the Blind's Directory of Services (1984). One must consider that bias does exist due to an underestimation of the legally blind population. Despite these limitations, no stronger enumeration statistics exist (Scholl, 1986:29-30). States were ranked from low to high levels of competition over clientele. The sample was drawn by selecting the 8 least (Connecticut, Virginia, North Carolina, Iowa, Florida, Wisconsin, Ohio, and California) and the 14 most competitive states (Idaho, New Mexico, Maine, Montana, South Dakota, Nevada, New Hampshire, Hawaii, Vermont, North Dakota, West Virginia, Georgia, Wyoming, and Alaska). The number of cases in low competition states was 226 with 220 cases in high competition states, which provided similar subsamples for comparative statistical analysis.

In the fall of 1985, a mail questionnaire was sent to those 446 agencies. 198 responses were generated of which 135 provided usable questionnaires to

reflect a response rate of 44.4%. An additional 114 more cases were actually represented because 10 state offices provided all of the statistics. When these additional cases are considered, the response rate rises to 70% which is above the level of acceptability (50-60%) that was set prior to the mailings.

Multiple regression analysis was used and numerous dummy variables and ratios were created. Overall, increased environmental competition had little or no impact on a wide variety of indicators of organizational size and structure (total number of services offered by the agency, total operating budget, amount spent per client, number of employees, ratio of professional to support staff, availability of personnel, and ratio of clients per staff). In addition, competition does not lead organizations to charge fees which could be a way to supplement constrained budgets. The only indicator of size that was affected by environmental competition was the number of board members, but membership guidelines for the board of directors and the use of staff as board members were not affected.

While environmental competition does not affect the size and structure of organizations, the rehabilitation process and client outcomes were affected. Increased competition over clientele led to greater retention even though the average length of time required to complete rehabilitation programs was not lengthened by potential client shortage. Agencies in high competition areas also tended to develop and rely more heavily on outreach programs to locate clientele.

In the final stage of the model, it was assumed that environmental competition would affect both the structure of organizations and the availability of scarce resources which would consequently lead to a variation in organizational coping behavior. Fiscal and personnel constraints were also expected to affect client outcomes. Monetary and personnel constraints did not

create differences in organizational coping behavior. Budgetary constraints also did not have any impact on referral or retention, but personnel shortage did lead to increased referral.

Based on these data one can conclude that environmental competition does not change the basic size or structure of blindness organizations. However, client outcomes were affected by environmental competition, personnel constraint, and indicators of organizational structure. Since agencies have less control over funding and other related scarce resources, clientele appear to be the manipulable resource which can be referred or retained to meet organizational needs. The population-ecology model has been used extensively to explain the behavior of voluntary associations which do not tend to have a captive membership pool from which to draw. However, this framework does not explain the behavior and structure of blindness rehabilitation agencies because the potential clientele do not have control over the selection of the agency or the rehabilitation process itself.

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THE CREATION OF CHRONICITY:  
AN INSTITUTIONAL CASE STUDY OF SOCIAL POLICY AND  
SEVERE RETARDATION IN THE PROGRESSIVE ERA

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The history of disability in America is largely the history of poverty or economic dependence. Certainly, affluent people have been affected by disability. In some prominent cases this experience precipitated efforts--backed by wealth and power--that helped change standard clinical practice and general public policy. Nonetheless, in various ways from colonial times to the present, public involvement with disabled citizens has largely revolved around the persistent difficulty of large numbers of disabled people to support themselves independently or through their families. More than one historian of deviance has argued that the crucial distinction in our nation's history of social welfare was the relatively early one between capacity and incapacity, the "able-bodied poor" and the "helpless." This was a distinction repeated many times within increasingly narrowly defined marginal populations. The process was especially pronounced in the evolution of services for feeble-minded and insane people. This paper presented a case study of how the distinction functioned within an institutional setting at the turn of the century.

An Institutional Case Study

The Rome State Custodial Asylum for Unteachable Idiots, located near Syracuse in upstate New York, officially opened its doors in May, 1894. It was the first public "idiot asylum" specifically designated to receive only

the most severely disabled of the retarded population. However, over the next 25 years, from 1895 to 1920, the evolution of the Rome institution took a dramatically different direction from its pre-ordained path of minimal care for the supposedly helpless few. By 1920, Rome had a national--even international--reputation for innovative programs of community placement and vocational training for people who were mildly retarded. This transformation of the Rome Asylum creates an interesting historical opportunity for anyone interested in the social construction of severe disability and chronic helplessness.

Rome's first superintendent, John Fitzgerald, admitted to the New York legislature in annual reports that little in the way of programming was going on at his new asylum. Indeed, Fitzgerald's eight-year tenure (1894-1902) understandably reflected an overriding concern with buildings and grounds. The residents remained locked inside the buildings for most of the day. Fitzgerald's status as an M.D. had nothing to do with his practical responsibilities. His position as head of a facility designated as purely custodial in purpose and meant to receive unteachable idiots--those deemed unimprovable by his own profession--was not a job held in high esteem by his peers. Custody and containment were the watchwords of Fitzgerald's tenure, not cure and training. That situation changed rapidly when the new superintendent, Charles Bernstein, took over from Fitzgerald.

Under Bernstein, Rome quickly had a brand new script with many new roles to fill. The "unteachable idiots" who composed the original cast for his institution, now served as Bernstein's offstage extras. Their implicit function was mainly to explain the occasional failures of his new stars: the legions of mildly retarded young adults who came to dominate Rome. By 1915, Bernstein

happily reported that 80% of the new admissions were now classed as "morons," or mildly retarded, where, at the turn of the century, 90% had been listed as idiots and imbeciles. In his very first annual report to the New York legislature, Bernstein notably dropped the practice of his predecessor of breaking down admission statistics according to functional level. Until the 1930s, Bernstein rarely discussed this lower functioning portion of the inmates at Rome, except as a boundary class marking the lower limits of productive potential. Instead, Bernstein's attention was aggressively placed on the need for increased space and admissions. Repeatedly, Bernstein would base his case for expansion on the grounds of economies of scale and the cost-efficient labor that more mildly handicapped inmates could provide in caring for the low grade adults and children.

### Conclusions

What points emerge from this brief account of Rome's early years? What relevance is this dinosaur of past policy to the current debates and reform initiatives in developmental disabilities? This brief case study of the Rome Asylum suggested at least two areas of relevance for the current generation of reformers.

First, the early history of Rome illustrates well the connection between incipient professionalism and the identification of a population requiring service. No move to professional respectability can base itself on a simple model of custodial housekeeping. Anyone can do that. At the same time, however, establishing credibility requires moderation in claims for improvement by "professional treatment." As the example of Rome illustrates, the social pressure to both accept an unteachable, chronic class and also assert one's expertise through instructional achievements with the inmates made the failure

of separate, purely custodial facilities almost inevitable. The teachable classes could establish the efficacy of Bernstein's methods. The unteachable classes provided a "saving remnant," as it were, by which to explain the inevitable failures. Those who failed to succeed did so because they were unteachable, not because they were not taught.

A second, and final, point. The category of chronicity was, above all else, an economic category, not an organic one. From this perspective, Bernstein's efforts can be explained from the economic basis of who among his charges could be made "useful." Some of his inmates -- the mildly retarded ones -- could, in fact, become productive, said Bernstein, and, therefore, deserved acceptance back into society. Beyond all of the more immediate reasons (e.g., inadequate funding, the Depression, overcrowding) for the ultimate failure of Bernstein's reform efforts, this implicit acceptance of the single standard of success (i. e., economic productivity) doomed his approach from the start. Bernstein did not challenge the social system that excluded his inmates, he merely called for a redistribution of the surplus population.

The example of Rome suggests, then, that any reform that accepts the imposition of economic utility as the price of social integration may condemn itself to an episodic and partial success. A more radical reform might refuse to identify work with employment. Mature capitalism defines people's worth by the sale of their labor rather than the gift of life itself. In our current and well-intentioned eagerness to have severely retarded people join this system, perhaps we echo the past in too readily accepting this commodification of culture. The marketplace demands a surplus of failures for the success of a few. And society, if unchallenged, will always find a place to abandon its failures.



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## Chapter IV

### Disability and Relationships

Societal reactions to persons with disability often involve stigma. The identity of the person with a disability may be discredited by others. The consequence is often social isolation or awkward, unscripted interactions between persons with disability and their nondisabled peers. There are a myriad of barriers that may exist for persons with disability (and for those without a disability) as they seek to develop friendships or sexual relationships.

In "Between Friends," Elaine Makas discusses her study (with Suzanne Cook) on friendships between disabled and nondisabled professionals who work in settings related to disability (e.g., rehabilitation, research). The data collection method was particularly creative. One researcher interviewed seven nondisabled professionals who had friendships with persons with disability. Another researcher interviewed six disabled professionals who had friendships with nondisabled persons. The researchers, acting as intermediaries, would pass questions from their respondents back and forth. Thus, persons with disability could ask questions of those nondisabled persons, and vice versa. Makas notes the important issues in these friendships: motivation (e.g., why would a nondisabled person want to have a friendship with a person with a disability?), focus of the friendship (e.g., do the friends have mutual interests beyond the issue of disability?), and so forth.

In "The Single Life and Disability: Responses to Ads in a Publication for Singles," Marjorie Newman addresses the issue of social isolation among those persons with a disability. Newman took out ads in a singles publication; one described qualities of a female seeking male companionship without mention of a disability; one year later she ran the same ad this time including "I have

difficulty walking due to an auto accident." Interestingly, many more men responded to the second ad. While there were certainly some respondents with suspect motives, Newman observed that the majority were serious respondents. Newman's study raises a number of interesting issues. First, is it ethical to advertise for companionship while doing a study? When should one inform respondents? Secondly, might ads in singles publications be an effective means for persons with disability to find companionship and break the barrier of social isolation? Thirdly, what are some of the important security issues: screening respondents effectively, and so forth?

## BETWEEN FRIENDS

By

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This paper is a re-analysis of a study conducted by Suzanne Cook and me (Cook & Makas, 1979) on the development of personal relationships between equal status disabled and nondisabled professionals who had met in settings associated with disability. The study involved extensive and repeated interviews with seven nondisabled and six disabled individuals who worked in disability-related fields (research, rehabilitation, advocacy, and sign language interpretation). Additional information was gathered in less formal discussions with other disabled and nondisabled professionals. Suzanne interviewed all nondisabled participants; I interviewed all disabled participants. As a nondisabled researcher in the field of disability, I served as Suzanne's primary informant. Sharon, a disabled colleague, was my primary informant.

One unique feature of our research was the inductive-deductive approach used. For the most part, Suzanne and I did not know one another's findings until the end of the study. Suzanne, for example, asked her interviewees to discuss their personal relationships with disabled acquaintances and friends. From these interviews, she generated questions for me to ask of the disabled informants. I, in turn, relayed questions raised by the disabled informants back to Suzanne to be addressed in her interviews with the nondisabled professionals. Thus, we served as conduits for an exchange of information between these two groups. Our focus was on areas in which the differing disability statuses of the interactants appeared to have played a role in the development of friendships.

The stranger to acquaintance stage of a developing relationship is strongly affected by the interactants' external characteristics (e.g., Berscheid & Walster, 1978; Huston & Levinger, 1978). Individuals will choose to strike up acquaintances with people who appear to have something in common with them. For most people, a difference in disability status might be seen as an apparent dissimilarity. For our specialized nondisabled sample, however, this did not appear to be the case. The nondisabled participants assumed, correctly or incorrectly, that they had something in common with disabled individuals: an interest in disability-related topics. Perceived similarity, however, may have been more questionable among the disabled professionals. Although the nondisabled persons had been encountered in disability-related settings, a situation suggesting shared interests, some disabled individuals questioned why the nondisabled persons were in such settings.

This ambivalence may be seen in one crisis found during the stranger to acquaintance stage of developing relationships: "motivation testing," in which the disabled person may question why the nondisabled individual has chosen a career related to disability. In some cases, this questioning is accompanied by "hostile bravado" (Goffman, 1963). Since disabled people have often been treated as "clinical populations" by researchers, it is not surprising that all three nondisabled researchers in the study recounted incidents in which their motives had been strongly and even rudely questioned. The service providers interviewed reported less motivation testing, possibly due to the fact that their roles might have been more clearly defined than those of the researchers. Suzanne found a decrease in motivation testing as the nondisabled person became better known. The disabled informants suggested that "motivation testing" was the result of simple curiosity, and that an



honest response usually resolves the issue. Both disabled and nondisabled participants, however, repeatedly told us that rudeness is rudeness, no matter who is the source. Sharon stated this very concisely: "Nondisabled people do not hold a monopoly on being idiots."

A second crisis which was reported during the early stages of relationships is "disability status clarification," a process by which the interactants acknowledge their differing disability statuses. A sign language interpreter in our study suggested one reason for this clarification:

It might be a defense mechanism, a presetting for rejection kind of thing, I don't think it's any different than an able-bodied person coming up and saying, "I'm married" or "I have a boyfriend, but let's be friends anyway." I don't see anything wrong with that. It's like being a Republican in a Democratic town--you warn people beforehand. I think these are things which could make a difference with people, and putting them out in the open first might be their way of handling it. (Cook & Makas, 1979, p. 37)

A third crisis which all nondisabled informants in our study reported is emotional distress. Although Katz (1981) suggested that this distress represents ambivalence caused by conflicting feelings of disgust and sympathy, the nondisabled people whom Suzanne interviewed, reported only reactions that Katz might classify as "sympathy." Sympathy, however, may be as offensive to a disabled person as disgust, and interacting with disabled people because of sympathy may be perceived as being as negative as avoiding disabled people because of disgust. Sharon suggested that sympathy itself is not wrong, and that she and other disabled people have similar emotional crises in dealing with those more disabled than they. However, she strongly advised that it was best for a nondisabled person not to show

these feelings to disabled people who are relative strangers, since some might be angered by them, and others might take advantage because of them.

Most nondisabled informants reported coping with this problem by seeking out other nondisabled friends who had had more experience with disabled people than they. Others reported that the nondisability of the friend was not a criterion for choice of empathetic ears. This may be due more to the fact that these nondisabled professionals did not have an easily identifiable nondisabled support group (e.g., other rehab nurses) than to any major philosophical differences among informants. Suzanne found that increased contact with disabled individuals seems to produce empathy with disabled people, rather than sympathy toward them.

Once past the stranger to acquaintance phase of a relationship, the decision as to whether the relationship should progress further is based, in part, on perceived similarities of attitudes (e.g., Knapp & Harwood, 1977; Lea & Duck, 1982). New crises emerge, however, at this point that are specific to interactions between people of differing disability statuses. In the Cook and Makas (1979) study, we found an overemphasis on disability conflict occurs when one, but not both, of the interactants is unwilling to discuss topics other than disability. This is frustrating because it emphasizes one point on which the interactants do differ, and it prevents the individuals from discovering points on which they are similar. The interactant refusing to discuss subjects other than disability may be either the disabled person or the nondisabled person. Some of the disabled and some of the nondisabled informants in our study reported feeling frustrated about always having to "talk shop." Others, however, confessed that they themselves might have steered many social interactions into discussions solely of disability-related issues. One nondisabled woman gave a somewhat mixed

message: "I, too, can get hung up on disability. I don't find any problem with this. I find that once a person has accepted his or her disability, they don't dwell on it" (Cook & Makas, 1979, p. 54).

A second crisis that is sometimes encountered at this stage of the relationship related to dependency. All of the nondisabled informants reported instances in which disabled individuals had requested unnecessary help from them. On the other hand, the disabled informants also reported being given unnecessary and unwanted help by nondisabled people. Responses to unnecessary assistance, either requested or given, were mixed. Nondisabled subjects' stances ranged from a strict "do it yourself" approach to a more peaceful, but less enlightening, "it takes less energy to do it than to argue about it" approach. Disabled informants' reactions also ranged widely, from a confrontational stand to one of resigned acceptance.

When Suzanne and I began our study, we assumed that service providers were less likely than researchers to develop close interpersonal relationships with disabled individuals. We thought that service providers, compared to researchers, would have had many more unequal status contacts with disabled people, and that they were more likely than researchers to have been trained not to get personally involved with their clients. We were surprised to discover, at least in our small sample, that this was not true. I now realize the mistake that led to this assumption. Although most service providers do have a great deal of professional, unequal status contact with disabled persons, and many have been trained to maintain an emotional distance from their clients, many nondisabled researchers have had similar experiences. We, too, often deal with disabled people as though they are not our equals, and we too, have been trained to treat our subjects/informants "objectively."

The main conclusion that Suzanne and I drew, however, holds true today: despite occasional stumbling blocks, including those that we, as disabled and nondisabled professionals alike, create, people of differing disability statuses can and do become friends. Hays (in press) suggests that surmounting crises, such as those discussed above, can actually enhance the intimacy of a relationship. The rehabilitation nurse whom Suzanne interviewed summed up our findings nicely:

If I were a prissy little professional, or knew someone as the Gall Bladder in Room 22 or the Pancreas in Room 21, I wouldn't find out the information I need. There are very few cases in which I wished I had been more professional.

(Cook & Makas, 1979, p. 61)

\* \* \* \* \*

I would like to acknowledge my gratitude to the individuals who participated in the original Cook and Makas study, especially Sharon; to Bob Hays for reviewing this paper; and, most importantly, to Suzanne Cook, my friend and colleague.

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THE SINGLE LIFE AND DISABILITY:  
RESPONSES TO ADS IN A PUBLICATION FOR SINGLES

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A major problem for persons with disabilities is that of social isolation. As a human being, the individual with a disability has the same needs for warmth and suaring, caring and closeness, for emotional and physical contact, as fellow humans. The unfortunate experience of those seeking companionship to fill such needs has often been that of rejection and shunning. The question that arises is, how to reach out to meet potential partners in a way that will maximize positive response while permitting screening to minimize negative reactions.

The research reported on here compares the response to two ads placed in a publication for singles in a large West Coast city. Both ads described the characteristics of a female advertiser, as well as the qualities she was seeking in a male companion, and differed only in that one of these ads included mention of a disability with the words, "I have difficulty walking due to an auto accident." The ads were each placed in September, one year apart, with the ad mentioning the disability being the second one placed.

Analysis showed a marked difference in both quantity of replies as well as characteristics of respondents. The first ad elicited 19 responses, while the ad including the mention of the disability garnered 62 replies. Of these showing an interest in the first ad, there were few who were highly educated. They presented a mixed bag, predominantly salesmen, and included a photographer, a french chef, and a musician.

Respondents to the ad which included mention of the disability were



predominantly well-educated, professional men. There were several college professors, architects, engineers, and more than a dozen computer programmers. The general economic status of this second group of respondents also tended to be higher than that of those who had replied to the first ad.

When one moves beyond the initial response, a sharp differentiation in behavior appears between the two groups. One third of the replies to the first ad were selected for further contact, with each of them being sent a letter describing the characteristics and interests of the advertiser--including the mention of the mobility impairment due to the auto accident. While one did actually telephone, nothing was ever heard beyond that from any of them again.

In contrast, respondents to the second ad who received follow-up contact were generally receptive--if not actually eager--to meet with the advertiser. Out of the 50 responses deemed to be seriously replying to the ad mentioning the disability, half were interviewed by the investigator--nine on actual dates, 12 by telephone and 4 through lengthy correspondence.

Further analysis permitted categorization of those who had responded to the ad mentioning the disability into four classifications of previous contact with disabilities. Of those who had personal experience with disability, nearly half had been injured in some kind of accident. Others had neuromuscular and/or degenerative conditions. Beyond the approximately 45 percent comprising the group with personal experience two other categories, approximately 20 percent each, consisted of those who either had a family member with a disability or who had had professional, work or social contact with a person with a disability. Finally, there was a small group of about five percent who said that they had never had any previous contact with disability. The status of contact for the remainder of respondents is unknown.

It was also possible to devise categories for what it was that respondents were seeking in answering the ad. Approximately 30 percent were, in some fashion, attracted by the image of a woman with some kind of limitation, for varying reasons. About half of these believed that such a woman

would be a "homebody" who would devote herself to making her man the center of her attention, and appreciative of his attention to her in spite of her having a disability. Some 30 percent of those who had been through accidents themselves, and had recovered their complete physical capabilities, were crusaders out to convince the researcher that, "if you really work at it and/or believe," she would also be healed. For others of this group, the investigator's difficulty in walking simply did not matter.

Men who had had contact with persons with disabilities through work or socially, were the ones who took the situation most in stride. The predominant attitude among these individuals was that it was simply there, but didn't really matter--it was other characteristics of the advertiser that were important. They were, as a group, the most relaxed and easiest to carry on a conversation with.

The few individuals who preferred to pretend that there was no disability, and who displayed discomfort at any mention of it, had no history of prior contact with disability either through personal experience or through contact with a person with a disability. It is important to note that while a few of the respondents might be described as colorful characters, there was no evidence of any really freaky types replying to the ad. Overall, the respondents presented a picture of a relatively healthy, straightforward group of people seeking companionship.

The majority of respondents were looking for a woman with sparkle and

a positive attitude. Several of them said that if the investigator was as independent, active and cheerful as was stated in the ad then, in view of the extra challenges facing her, she must really have something going for her. What was heard repeatedly was that the individual wanted to meet someone with that kind of spirit.

The results of this research indicate that personal ads may provide one avenue of solution for persons with disabilities to seek potential partners in a way that effectively screens much of the rejection that can occur in other initial encounter situations, thus encouraging favorable results.

Two questions that require further investigation are whether this positive response will also hold true when it is a male who places the ad--taking into account that males have been found to receive fewer responses than female advertisers in the general population--and whether it is valid throughout the country or just a peculiarity of the region in which the research was carried out, where the practice of placing personal ads has been developed into a fine art.

An important implication that evolved from analysis of the data reported on here is the role of previous contact with a person with a disability in either the workplace or social settings. It was found that the same effect did not occur if the person with the disability was a family member. It is clear that, at least in this limited study, the greater the occupational and/or social contact of the potential respondent with individuals who have disabilities, the more open such a person might be to a more personal, potentially romantic involvement with someone who has a disability.

To put it another way, the greater the exposure the greater the potential for nondisabled persons to see the person as a whole rather than to focus on, and be put off by, the disability. This simultaneously

enlarges the pool of prospective partners for romantic involvement, and lessens the chances of rejection because of aversion to a disability. This research has demonstrated that persons who are members of this category are the most likely to respond positively to a personal ad placed by someone with a disability, the ad provides an effective means of reaching such individuals.



## Chapter V

### Studies in Disabilities: Economics and Policy

Social researchers concerned with disability are increasingly coming to appreciate what disability rights advocates have understood from their beginnings as a movement, that the position of groups in modern society is largely determined by their ability to influence economic aspects of public policy. Because of the growing appreciation of the importance of economic policy matters, disability researchers are currently exploring a wide range of topics concerning such issues. The three articles included in this chapter reflect this growing interest and concern.

In "Estimating Earnings Impact of the Vocational Rehabilitation Program," Robert C. Dolan and David H. Dean employ quantitative research methods that take advantage of recent methodological advances in the general manpower training literature and the availability of longitudinal earning data to assess the impact of vocational rehabilitation services on the earnings of disabled men and women. The study examines earnings one and two years before and after the period in which vocational rehabilitation services were received. The findings are presented by gender and disability.

Both men and women were found to experience substantial improvements in income as a result of participating in vocational rehabilitation services. Earning impacts for both men and women ranged from \$1000 to \$2000. Physically disabled men and mentally retarded women experienced the greatest earnings improvements.

In "An Evaluation of the Prospective Payment System for Medicare Patients," David Pfeiffer and Pamela Christian explore the impact of the Reagan Administration Medicare funding reforms on the quality of health care received by the elderly. Of particular concern is the quality of health care available



to elderly persons needing long term care.

Under Title IV of the Social Security Amendments of 1983, the Prospective Payment System (PPS) for Medicare was established. With this system, patients are assigned to a Diagnostic Related Group (DRG) upon release from a hospital stay. This assignment determines the amount the hospital can be paid for its services.

In developing their study, Pfeiffer and Christian focus on Medicare Service data from the years 1981 to 1984 when the Prospective Payment System was in the process of being established. These data are derived from the records of a sample of 27 DRG's all of which involve conditions requiring long term care. The 27 DRG's include a total of 9,895 Medicare discharges.

The major finding of this study concerns the fear that seriously ill patients will be discharged prematurely under the Prospective Payment System (PPS). In regard to this question, Pfeiffer and Christian found that for 1984, the first full year that federal PPS reimbursement had been in effect, the average length of hospital stay was far below the average length of stay of the three earlier years. It was also found that the number of Long Term Care (LTC) "Medicare patients going home under selfcare increased with PPS." Findings such as these suggest that the fears of advocates for the elderly concerning the Reagan Administration Medicare funding reforms are more than justified.

In "The Political Economy of British Disability Policy," Richard K. Scotch examines the United Kingdom's programs and policies dealing with disability and disabled people and compares these to those of the United States. Scotch identifies the National Health Service (NHS) and income maintenance programs as the primary elements of British disability policy. Scotch also examines the influence of British law on the civil rights of disabled people, the status of both the disability rights movement and the independent living movement, and

the structure and functioning of the British political institution. The author concludes by noting that the 'British welfare state guarantees minimum economic and social entitlement in income, housing, health care, and education, but does not emphasize individual rights." By contrast, Scotch suggests, "the American welfare state places much more of an emphasis on individual procedural rights....but substantively isolates many disabled people by providing far more limited benefits" (Scotch, 1988:104).



## ESTIMATING EARNINGS IMPACTS OF THE VOCATIONAL REHABILITATION PROGRAM

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This article examines the earnings impacts of services provided by a state agency of the Vocational Rehabilitation (VR) program. This study is noteworthy as a first attempt to examine VR's effects drawing upon recent developments in the general manpower training literature. These advances include various comparison-group methodologies to control for pre-program differences (Ashenfelter & Card, 1985; Dickinson et al, 1986; Westat, 1982), the "fixed-effect" specification for identifying earnings change within a nonexperimental design (Ashenfelter, 1978; Cooley et al., 1979), the significance of "pre-program dip" in program evaluation (Ashenfelter, 1975, 1978; Bassi, 1983; Kiefer, 1979; LaLonde, 1986) and correction procedures for assorted sources of selection bias (Bassi, 1984; Heckman, 1979; Nickell, 1981). However, these modern techniques require longitudinal earnings data which are generally unavailable within the established VR recording process. Through the cooperation of the Virginia Department of Rehabilitative Services (VDRS) and the Virginia Employment Commission (VEC), we have implemented a data link by which we obtain the necessary longitudinal earnings records for VR clients. Due to this data improvement we are able to estimate earnings impacts using techniques previously unadaptable to VR. Conceptually, however, this synthesis of the literature is necessarily qualified due to intricacies associated with serving a disabled clientele. The contribution of this paper is thus twofold. First, we introduce a data set for VR evaluation that is enhanced in the respects necessary to permit adoption of the recent evaluative techniques.

However, we also emphasize conceptual issues that distinguish assessment methods for VR within the general realm of manpower program evaluation.

The basic objective in the evaluation of manpower programs is to identify the net impact of services on a client's permanent earnings path, (i.e. how much more does a trainee earn following treatment vis-a-vis what they would have earned at an equivalent time in the absence of training). In this context, VR is a manpower training program with an important difference--the VR client is work disabled. This fact raises evaluation considerations which are unique to VR. The optimal methodology for assessing training effects is a pure experimental design in which participants are randomly assigned to treatment and control groups. But this approach is infeasible in the case of VR due to the ethical/legal issue of randomly denying the services of a public program to otherwise eligible clients. Alternatively, a "comparison" group methodology can minimize pre-enrollment differences between the treatment and non-treatment groups that otherwise tend to bias measured earnings impacts. For our purposes, Status 30 clients appear as the most appropriate comparison group. The Status 30 client is essentially a dropout. This cohort has conceptual appeal for several reasons. First, Status 30 clients had the motivation to apply to VR and they met the agency criteria of eligibility. Second, it is likely that both successfully rehabilitated clients as well as dropouts experience similar depreciations in their human capital which lead them to apply to VR. Third, because the Status 30 clients are closed prior to implementation of their treatment program, the only service received by the comparison cohort is a diagnostic evaluation. Diagnosis alone is unlikely to have significant effects on the client's human capital, and thus should not affect the comparison group's permanent earnings paths. In short, the Status 30 client is a viable comparison group for evaluation of VR.

The earnings model used to estimate treatment effects is based on the fixed effects estimator as introduced by Ashenfelter (1978). This model initially assumes that the earnings structures are similar both over time and for the respective treatment and comparison groups. The conventional model of earnings used with longitudinal data is of the form:

$$(1) \quad Y_{it} = aD_i + bX_{it} + U_t + U_{it}$$

where  $Y_{it}$  is earnings of individual  $i$  in time period  $t$ ;  $D_i$  is a binary variable indicating whether the client participated in the VR program; and  $X_{it}$  is a vector of control variables of individual characteristics that affect earnings. The error term is comprised of three components: 1) an individual-specific component  $U_i$  which is constant over time (i.e. fixed), 2)  $U_t$ , an error specific to time  $t$  and constant across individuals; and 3) an error term specific to individual  $i$  at time  $t$ ,  $U_{it}$ , which may be either uncorrelated over time in a random effects estimator, or a serially correlated transitory disturbance (e.g. pre-program dip). The value of longitudinal data is that any correlation between the error term and program participation can be eliminated by differencing equation (1) over appropriate pre- and post-treatment time periods to remove the "fixed effect." This procedure yields:

$$(2) \quad Y_{it} - Y_{is} = aD_i + b(X_{it} - X_{is}) + (U_t - U_s) + (U_{it} - U_{is})$$

where  $t$  denotes a post-program period and  $s$  is a period prior to participation.

In essence, the fixed effects estimator assumes that any earnings change between these periods can be attributed to changes in personal characteristics and environmental factors as well as VR program participation. This model assumes that any unobserved factors that may be correlated with VR participation and earnings are either constant or change only slightly over time. Therefore, any bias in the treatment effects due to unobserved differences between the Status 26 (successes) and Status 30 (dropouts) clients



can be controlled for statistically by differencing a base-year and an outcome-year earnings equation. In its usual formulation, control variables in the  $X_{1t}$  and  $X_{1s}$  matrices that are invariant over time (sex, race, education) drop out during the differencing process. However, if the functional relationships predicting earnings differ between the comparison and treatment groups, then these independent variables should be reintroduced into the model. Given the different effects of such variables across disability types, we include such a vector of demographic control variables in our "difference-in-differences" specification. For our model we have chosen earnings during the period one and two years before and after the interval of time during which VR services were received for the difference estimates.

The choice of the appropriate pre- and post-program earnings years is an important part of the difference-in-differences specification (Heckman & Robb: 1985). In theory, there can be as many estimates of the treatment effect as there are pre-treatment years of earnings. If the model is properly specified, each of these estimates should be similar as long as the base period chosen is one year prior to those used by the program participants or administrators as the basis for selection into the program.

Table 1 presents the regression-corrected difference estimates of VR service impacts. The results are presented by gender and disability. The two symmetric time periods appear side-by-side within each stratification. These results invite four lines of interpretation regarding the use of longitudinal data for measuring earnings impact of VR services: 1) treatment effects by gender; 2) treatment effects by disability; 3) the explanatory value of including additional control variables; and 4) the sensitivity of measured earnings gains in different pre- and post-treatment periods.

First consider the treatment effects by gender. For both male and female groups, the treatment effect dummy variables are generally significant and of the expected sign. The coefficients suggest net earnings impacts are in the range of \$1000-2000 for both men and women depending on the nature of their disability. In percentage terms, the gains for men and women are greater for women, who have a lower initial level of annual earnings.

The disability stratification is quite revealing. Observe that physically disabled men and mentally retarded women enjoy the largest significant earnings improvements vis-a-vis other disability cohorts. The earnings gains for men range from \$1118 to \$2084, depending on which years one uses in the change in earnings estimator. In comparison, physically disabled women average gains of roughly \$1200 to \$1800. Note also that, for women, the treatment effect is significantly stronger in the mentally retarded cohort than the physically impaired. These increases range from \$1854-2229. Given the generally lower level of earnings for mentally impaired clients, this represents a much larger percentage increase in earnings. In contrast, the training impacts for mentally disabled men are much smaller and statistically insignificant for the period two years prior to and after receipt of VR services. The opposite situation exists for the emotionally disabled cohort. Emotionally impaired men experience a significant earnings gain of roughly \$1400 to \$1800, again depending on time frame, while treatment effects for women are smaller than for the other two female disability cohorts. Of course, this latter result is unsurprising in view of the very low R-square and F-statistic for this cohort. In other words, our model has not accounted for the factors in the labor supply decisions of emotionally impaired women.

The usefulness of including the control variables in the difference estimation are unclear. Overall the insignificance of these controlling

factors tends to support the contention that there is not substantial differences -- at least observably so -- between the successfully rehabilitated client and those clients who self-select out of the program after being accepted for services.

We offer a similar judgement regarding the significance of the time frame applied in the difference estimation. In general, earnings differences two years pre- and post-training exceeded those for one year before and after the VR training period. Other studies have found that the choice of base year may determine the magnitude of the treatment effect (Ashenfelter & Card; 1985). However, as long as the base year is chosen prior to any permanent or transitory "pre-programm dip" in earnings, then we would expect to see similar treatment effects.

TABLE 1

Regression-Corrected Difference Estimates  
of the Impact Of VR Services on Client Earnings  
(T-Ratios in Parentheses)

## Earnings Equations for Male Clients Terminated from the VDRS in 1982

| Independent Variables    | Physical Disability (n=1518)                                     |                      | Mental Disability (n=741)  |                      | Emotional Disability (n=432)                                     |                      |
|--------------------------|--|----------------------|--|----------------------|--|----------------------|
|                          | Dependent Variable Change in Earnings from Pre- and Post-VR for: |                      | Dependent Variable Change in Earnings from Pre- and Post-VR for: |                      | Dependent Variable Change in Earnings from Pre- and Post-VR for: |                      |
|                          | One Year   | Two Years            | One Year   | Two Years            | One Year   | Two Years            |
| Intercept                | 130.91<br>(0.09)   | 4076.08<br>(2.19) *  | 2525.12<br>(1.88)  | 8092.95<br>(4.99) ** | -1724.93<br>(0.75)   | 3117.11<br>(1.07)    |
| Age (at Referral)        | 42.49<br>(0.57)  | -195.01<br>(2.07) *  | -154.22<br>(1.67)  | -456.55<br>(4.11) ** | 1.38<br>(0.01)   | -384.58<br>(2.17) *  |
| Age Squared              | -1.37<br>(1.41)  | 0.81<br>(0.66)       | 2.47<br>(1.75)   | 6.20<br>(3.64) **    | -0.56<br>(0.27)  | 5.09<br>(1.95)       |
| Race (1=White)           | 105.60<br>(0.31)   | -748.99<br>(1.74)    | -261.97<br>(0.76)  | -245.35<br>(0.59)    | -102.42<br>(0.23)  | 333.17<br>(0.58)     |
| Years of Schooling       | 68.75<br>(1.45) **   | 121.02<br>(2.02) **  | 91.32<br>(2.77) **   | 54.55<br>(1.37)      | 238.21<br>(3.50) **  | 239.10<br>(2.77) **  |
| Treatment Effect         | 1117.72<br>(2.96) **   | 2083.82<br>(4.35) ** | 865.08<br>(2.34) *   | 585.94<br>(1.32)     | 1400.81<br>(3.27) **   | 1798.44<br>(3.31) ** |
| Adjusted R-square        | 0.03   | 0.07                 | 0.02   | 0.03                 | 0.06   | 0.05                 |
| F-statistic for equation | 8.3  | 21.59                | 3.24   | 5.01                 | 5.22   | 4.68                 |

## Earnings Equations for Female Clients Terminated from the VDRS in 1982

| Independent Variables    | Physical Disability (n=1290)                                     |                      | Mental Disability (n=393)  |                      | Emotional Disability (n=390)                                     |                     |
|--------------------------|--|----------------------|--|----------------------|--|---------------------|
|                          | Dependent Variable Change in Earnings from Pre- and Post-VR for: |                      | Dependent Variable Change in Earnings from Pre- and Post-VR for: |                      | Dependent Variable Change in Earnings from Pre- and Post-VR for: |                     |
|                          | One Year   | Two Years            | One Year   | Two Years            | One Year   | Two Years           |
| Intercept                | -1272.71<br>(1.23)   | -53.81<br>(0.04)     | 790.08<br>(0.52)   | 845.74<br>(0.45)     | -1530<br>(0.69)  | -1517.46<br>(0.56)  |
| Age (at Referral)        | 74.58<br>(1.46)  | 32.27<br>(0.52)      | -99.29<br>(1.00)   | -133.89<br>(1.10)    | 44.71<br>(0.38)  | 74.48<br>(0.52)     |
| Age Squared              | -1.32<br>(1.97) *  | -1.29<br>(1.58)      | 1.51<br>(0.99)   | 2.02<br>(1.08)       | -0.45<br>(0.28)  | -1.53<br>(0.78)     |
| Race (1=White)           | 162.42<br>(0.71)   | 119.83<br>(0.43)     | -302.42<br>(0.87)  | -178.74<br>(0.42)    | 630.59<br>(1.36)   | 969.37<br>(1.71)    |
| Years of Schooling       | 38.14<br>(1.01)  | 16.07<br>(0.35)      | 96.49<br>(2.86) **   | 158.50<br>(3.82) **  | 48.30<br>(0.63)  | 1.53<br>(0.02)      |
| Treatment Effect         | 1234.63<br>(3.93) **   | 1797.31<br>(4.71) ** | 1854.32<br>(4.50) **   | 2228.91<br>(4.40) ** | 1116.81<br>(2.36) *  | 1368.22<br>(2.37) * |
| Adjusted R-square        | 0.02   | 0.05                 | 0.07   | 0.08                 | 0.02   | 0.03                |
| F-statistic for equation | 6.07   | 12.61                | 5.98   | 6.85                 | 1.68   | 2.16                |

\* Denotes significance at the .05 level

\*\* Denotes significance at the .01 level

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## AN EVALUATION OF THE PROSPECTIVE PAYMENT SYSTEM FOR MEDICARE PATIENTS

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One of the initiatives of President Ronald Reagan in 1981 was to reduce the cost of Medicare while at the same time calling it one of the protected programs which comprised the so-called "safety net" for citizens in need. The result was the Social Security Amendments of 1983 which became PL 98-21. Title IV of this legislation established the Prospective Payment System (PPS) for Medicare.

Upon discharge each patient under the PPS is assigned to a Diagnostic Related Group (DRG). The hospital (with some exceptions) is paid an amount according to the DRG. The DRG is determined by the principle diagnosis, the existence of comorbidity, complications, age, and sex. Some hospitals found that they made money from certain DRG's and lost on others. The hospitals, however, generally opposed the DRG PPS because they "lost" money.

Advocates for the elderly were concerned that the PPS would lower the quality of care. In addition, since the amount paid was tied into the LOS, they said abuse would happen. Patients would be discharged when the mean LOS was reached whether they were ready or not.

The Office of Health Care Policy in the Massachusetts Executive Office of Human Services was very concerned about the effect of PPS upon the most vulnerable of Medicare patients, those patients most likely to need Long Term Care (LTC). In order to determine the impact of PPS upon the most vulnerable of Medicare patients, a sample from five representative states



was drawn of the 18 DRG's most closely related to LTC (Meiners and Coffey, 1985) plus nine DRG's closely related to LTC in Massachusetts (Bellefeuille, 1986) for the years 1981 to 1984. One state (New Jersey) had a PPS for all of the four years under study. It is the only state to have had a PPS in 1981 and 1982. Two states (Massachusetts and New York) did not have PPS during the four year period. Two states (California and Michigan) started PPS in 1983 and had it for part of the time period. However, the 1981 data for Michigan and the December 1984 data for all five states is not available. (King, 1986) In addition, data for hospitals with less than 2,000 discharges in a given year is not provided by HCFA. The total number of Medicare discharges (all DRG's) for the five states during this time period was 8,594,397. From this population a sample of the 27 DRG's related to LTC was drawn totaling 9,895.

Many of the early critics of PPS predicted that the financial burden of Medicare would only be switched to the states' LTC system with little or no overall dollar savings. Other analysts observed that it appeared to be happening. Hypothesis One is that there is a statistically significant positive correlation between LTC related Medicare discharges to LTC and (a) the year of discharge and (b) when PPS is in effect.

The results show that the relationship between the year of discharge and going into the LTC system is clearly statistically significant (using chi square,  $p < 0.00005$ ). However, with such a large sample ( $n=9144$ ) statistical significance should not be surprising. The correlation ( $\gamma=0.12$ ), while positive, is not large at all. The results further show that the relationship between PPS being in effect and going into the LTC system is also statistically significant (using chi square,  $p=0.04$ ). But this time the correlation ( $\gamma=-0.10$ ) is negative while also being

quite small. Hypothesis One is rejected.

PPS critics say that Medicare patients will be unnecessarily shifted from one health care facility to another in order to receive reimbursement. A patient too ill to go home who has reached the DRG ALOS will be sent to a nursing home for several days and then readmitted. There is some evidence that such shifts are occurring, but unless one is able to follow specific Medicare beneficiaries it is difficult to test this assertion. Nevertheless, some data concerning the source of hospital admissions is available in the sample. Hypothesis Two is that there is a statistically significant positive correlation between LTC related Medicare admissions from other health care facilities and (a) the year of admission and (b) when PPS is in effect.

The results show that the relationship between the year of admission for LTC related Medicare patients between the year of another health care facility is random. They also show that the relationship with PPS is statistically significant (using chi square,  $p=0.002$ ), but the level of correlation ( $\gamma=-0.14$ ) is low and negative. However, for 1984, the first full year of federal PPS reimbursement, all of the data regarding source of admission is missing because HCFA was changing from one data gathering procedure to another. Perhaps its inclusion would change the results. With this caveat, Hypothesis Two is rejected.

Critics and advocates charge that seriously ill patients are to be discharged prematurely under PPS. The anecdotal history is replete with examples of seriously ill patients being discharged too early. This one point is the most politically sensitive one which opponents of PPS make. Hypothesis Three is that there is a statistically significant decrease in the length of stay of seriously ill LTC related Medicare

patients over (a) the four year time period and (b) when PPS is in effect.

There is no measure of severity of illness in the HCFA data even though many analysts call for its inclusion. This lack makes the testing of Hypothesis Three tenuous. Nevertheless, a surrogate for severity was constructed by designating those who were not discharged to home, self-care as being more seriously ill than those who were so discharged.

Using one way analysis of variance, the results show that there is a statistically significant difference ( $p=0.002$ ) between the average lengths of stay over the four year period for the more seriously ill LTC related Medicare patients. However, the mean for 1983 slightly exceeded that of 1982. The 1984 mean, on the other hand, is far below that of the other three years. The same result ( $p=0.001$ ) is found when comparing PPS in effect and not in effect. Hypothesis Three is accepted.

What is occurring to LTC related Medicare patients under PPS? The acceptance of Hypothesis Three shows a statistically significant decrease in the average LOS of seriously ill LTC related Medicare patients. At the same time, the results show another fact. The number of LTC related Medicare patients going home under selfcare increased with PPS. Was this result of better medicine? advances in home based selfcare? better planning? or a lack of room in the LTC system? It was not because of better medicine, advances in home based selfcare, or better planning. Home visits by nurses and health care aids increased under PPS. Beds in the LTC system remained fairly constant with a growing waiting list. A greater number of the more vulnerable Medicare patients under PPS were discharged seriously ill and with no other place to go, went home. At home they received services paid for in part by the states and often returned sooner than expected to the hospital. A larger number of them

died or lived lives of more diminished capacity than expected under PPS.

This last conclusion is an inference from the data used to test the hypotheses. It is not firmly established by the statistical testing because the needed variables are not available. While some studies are underway to test this conclusion, it will be some time before they are completed. In the meantime, more persons will die or suffer from the conditions established under PPS. While defenders of PPS can say that a number of persons will die and suffer no matter what system is used, its hastening by a policy (PPS) which is designed to save dollars is deplorable.

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## THE POLITICAL ECONOMY OF BRITISH DISABILITY POLICY

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This paper concerns changes in British disability policy since the 1960s, with a particular focus on the evolving political context within which policies have been developed and implemented. The growth of advocacy organizations representing disabled people is examined in relation to the growing policy emphasis on increasing the access which disabled people have to the major institutions of British life. Differences between policies and politics in the United States and the United Kingdom are analyzed in relation to differences in contextual factors such as governmental structures and processes, the structure of the delivery system for services to disabled people, the availability of resources, and cultural assumptions about disability.

During a five week study visit in 1986 to Great Britain under the auspices of the World Rehabilitation Fund's International Exchange of Experts and Information in Rehabilitation, a number of individuals were interviewed concerning recent trends in disability policy and disability politics in the United Kingdom. Persons contacted included representatives of a wide range of organizations of disabled people and organizations providing services to disabled people, as well as several public officials and scholars with involvement in disability issues. Interviews were supplemented by a review of the British literature on disability policy in recent decades, as well as available archival materials on the various organizations.

While the overall scheme of benefits, services, and protection for individuals is quite complex, the most important elements in British disability policy are the National Health Service (NHS) and the income maintenance

programs. The NHS was not specifically designed for disabled people, but there is an extensive and complex system of categorical cash entitlements for disabled people incorporated into the British welfare state, including programs for veterans and for people who have been injured in industrial accidents. There is also a confusing range of payments available for individuals with specific impairments or functional limitations. The result is an overall system with a number of inconsistencies and, some would claim, inequities, and there have been a number of proposals advanced to consolidate disability benefit programs into a more universal system.

In terms of civil rights, Britain has enacted a number of statutes which call for greater access and participation for disabled people, including a program of quotas for employment established after World War II and the 1970 Chronically Sick and Disabled Persons Act. The purposes of the 1970 Act included increasing access to schooling, housing, and public facilities, ensuring participation by disabled people in policy-making bodies, and improving institutional and community services. The Act appears to have had a powerful impact on public awareness about disability, but has had limited success in improving access or upgrading services.

The disability rights movement in the United Kingdom is not as well developed as its counterpart in the United States. Nevertheless, there are a number of grass-roots and national organizations which influence policy, largely through informal consultation in policy formulation in Parliament and the administrative bureaucracy. Major national organizations include the Royal Association for Disability and Rehabilitation, the Disability Alliance, the Disablement Income Group, the Union of the Physically Impaired Against Segregation, and the British Council of Organizations of Disabled People. There are also a number of local organizations, some of which cross disability

lines, and the beginnings of an independent living movement. Many movement activists characterize it as divided among organizations for disabled people, whose leadership often includes service providers and philanthropists, and organizations of disabled people, whose leadership and membership is limited to individuals with disabilities.

The structure of British political institutions somewhat constrains the ability of these disability rights advocacy groups to influence policy. Because policy objectives and priorities are chosen largely through the major political parties, it is more difficult for individual political entrepreneurs to promote disability issues than in the United States, where individual legislators play a far more significant role. While some elements in the Labour Party have been receptive to enacting anti-discrimination and accessibility protection for disabled people, disability issues have been of generally low priority, particularly in the context of the economic difficulties facing Great Britain in the past decade and in the face of the Thatcher government's agenda of limited government and privatization.

Differences between disability policy in the United States and the United Kingdom are consistent with larger institutional differences between the two nations. The British welfare state guarantees minimum economic and social entitlements in income, housing, health care, and education, but does not emphasize formal individual rights. The American welfare state places much more of an emphasis on individual procedural rights, with important implications for formal participation by disabled people in societal institutions, but substantively isolates many disabled people by providing far more limited benefits. Future cross-national comparisons of disability policies should address policy contrasts and similarities in relation to such institutional differences.



## Chapter VI

### Aging, Chronic Illness and Disability

With the rapid aging of the population in the developed world and the clear relationship between aging, chronic illness and disability, social scientists concerned with disability increasingly turn their attention to questions pertaining to chronic illness and disability in late life. Social scientists are currently exploring questions concerning the demographic dimensions of aging, chronic illness and disability; the nature and social dynamics of chronic illness and disability in late life; the social impacts of chronic illness and disability in late life; the changing service needs confronting a society with an aging of the population; housing needs; and policy implications.

The growing awareness of the problems of aging, chronic illness and disability is just beginning to result in a significant social scientific research response. Much work remains to be done. The three articles included in this chapter reflect the growing awareness by social scientists of the changing nature of the problems of chronic illness and disability in a world where the population is rapidly aging.

In "Blind Nursing Home Residents: The Newly Disabled," Joan Retsinas and Patricia Garrity assess the role visual impairment plays in causing the apathy, dependence, immobility and isolation among visually impaired nursing home residents. Data for the study were derived from 16 recently discharged or current visually impaired residents of a 160-person nursing home and included information concerning health status (including visual impairment, hearing impairment and other "other diagnoses"), self-care independence, social interaction, interest in the world outside the institution, mobility, and other background information.



The visually impaired residents included two types of experience with disability: ten of the residents included in the sample had become visually impaired before moving to the nursing home while the other six had become visually impaired after moving into the home. Retsinas and Garrity devote the majority of their study to identifying the differences in the life experiences of the persons in each of the visually impaired categories.

Persons who had become visually impaired after moving to the nursing home were found to be more limited than persons who had become visually impaired before moving to the home. "The latter [group] were less likely to be dependent for self care, socially isolated, disinterested in the outside world, and immobile" (Retsinas and Garrity, 1987: 112).

Retsinas and Garrity also found that among the residents who had become visually impaired before they moved into the nursing home and were experiencing limited functioning, the condition appeared to be caused by factors other than visual impairment. Many members of this group had other impairing conditions in addition to visual impairment. The persons of this group who were isolated appeared to be so because they lacked mobility.

On the other hand, for residents who had become visually impaired since moving to the nursing home and were experiencing limited functioning, the primary cause appeared to be visual impairment. "Only one [person] had limited hearing; none were confused; yet all were dependent for self-care." The isolation of members of this group was "probably the result of their [visual impairment]" (Retsinas and Garrity, 1987: 115).

Retsinas and Garrity conclude their study with a series of recommendations for training nursing home staff members in order to allow them to better serve visually impaired residents.

In "Osteoporosis As a Chronic Illness for Women: Medical and Feminist

Self-Help Perspective," Kathleen I. MacPherson presents the medical and feminist approaches to osteoporosis and its treatment. Under the medical model, osteoporosis is conceived of as a post-menopausal disease caused by lowered levels of estrogen in the body. Osteoporosis screening and hormone-replacement therapy are generally recommended as the appropriate means of prevention.

On the other hand, under the feminist self-help approach, osteoporosis is conceived of as a normal part of aging that only becomes problematic when fractures occur. A program of weight-bearing exercise throughout the lifecycle and a nutritious diet rich in calcium is generally recommended as the approach means of prevention. The feminist approach also emphasizes the structural factors in the United States that make prevention of osteoporosis difficult, factors such as the impact of income inequality on diet, widespread unemployment, a profit driven pharmaceutical industry, and the commodification of medical care.

Finally, in "Chronic Illness, Coping Resources and Psychological Distress Among the Rural and Urban Black Elderly," J. Gary Linn, Baqar A. Husaini and Richard Whitten-Stovall explore the relationship between chronic illness and depressive symptoms among rural and urban black elderly. Data for this study were derived from interviews with 398 elderly blacks from rural West Tennessee and 327 elderly blacks from Nashville, Tennessee. The data were analyzed using multiple regression and other standard quantitative techniques.

The best predictor of depression for both rural and urban elderly blacks was the number of chronic illnesses reported by respondents. Acute stress, however, was found to produce significant depressive symptoms in urban elderly blacks, but not rural elderly blacks. Finally, low income elderly blacks from both rural and urban areas were found to be at greater risk of experiencing

depression while "elderly blacks with a greater sense of personal control appear to be less vulnerable to the negative psychological effects of chronic disease" (Linn et al., 1987: 129).

## BLIND NURSING HOME RESIDENTS: THE NEWLY DISABLED

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A substantial literature documents the progress of blind people in the non-institutional world, but not in the institutional world. Although the majority of blind people are old, the blindness literature has focused on children and employable adults (Clark-Carter 1983; Gross 1973; Scott 1969). Researchers have described efforts to keep elderly people out of institutions (Evans et al 1982; Levy et al 1983; Wainapel 1964). Gerontological researchers have focused on residents who impede efficient management. Ironically, the blind resident who never leaves bed is an easy patient (Snyder et al 1978); and research (Avorn & Langer 1982; Baltes & Barton 1979; Baltes et al 1983; Mikulic 1971; Solomon 1982) suggests that staff may unwittingly "induce" patient dependence. The few researchers to study blind nursing home residents, however, highlight their apathy, dependence, and immobility (Culek 1981; Evans et al 1982; Hill & Harley 1984; Mummah 1975).

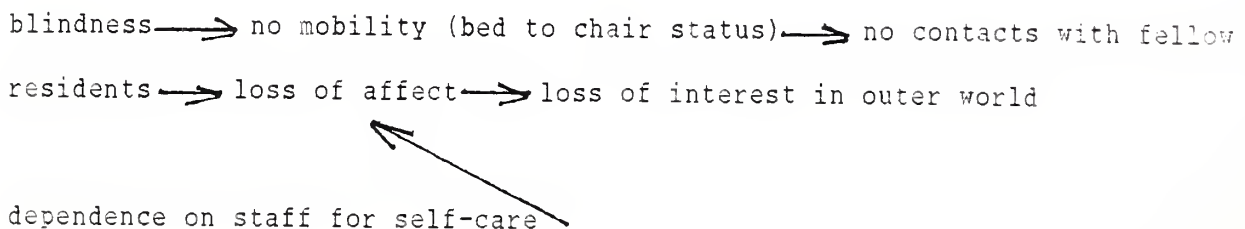
It is plausible to blame that immobility, dependence, and isolation on the institution's inability to accommodate blind people. First, the facility is a "physical setting minimal in olfactory, gustatory, tactile, visual and auditory stimulation" (Carolan 1973). Smells of urine and antiseptic solutions; tastes, of nutritionally adequate yet bland food. Tactile guides are smooth corridors and institutional furniture. Rarely do nursing homes offer residents easy access to outdoor gardens and walkways. Recreational activities are usually

geared toward those who can see. Even the noises are a cacophony of televisions and anguished screams.

Second, staff, like most sighted people, are uncomfortable around the blind (Davis 1969; Rickelman & Blaylock 1983; Scott 1969; Siller 1967); and they may not linger to chat or swap anecdotes. The "cuelessness" of blind-sighted conversations may make the blind partner eager to direct the conversation to specific tasks, distant psychologically (Kemp & Rutter 1986). More critically, staff do not know how to help the resident "learn" this new facility. Indeed, staff frightened that a blind person will fall may restrict him/her to the bedroom. Immobile patients are not a problem in a nursing home, so that staff have no incentive to help a blind resident learn the corridors (Hill & Harley 1984). And staff do not know simple protocols: the need to speak on entering a room, to tell a resident before leaving, the danger of half-opened doors or misplaced wheelchairs (Mummah 1975).

Third, the withdrawn, isolated resident is not an anomaly. Gustafson (1972) called "dying" the career of the nursing home resident. Even when blind people are not expected to die shortly, are not in pain, and are not confused, they rarely enter into the social life of the nursing home (Evans et al 1982). They behave like people about to die--and in the nursing home that role is legitimate.

Model A shows the interaction between immobility, dependence, and subsequent depression.



Intuitively the model makes sense. Staff are not trained to help blind residents maneuver in the nursing home, are generally uncomfortable with the blind, and may let residents stay in bed. Immobility leads to social isolation, which in turn leads to a loss of affect, apt to result in general disinterest. Furthermore, residents dependent on staff for self-care may lose self-esteem.

### Research

This research tested such a model by examining the lives of 16 recently discharged or current blind residents in a 160-bed nursing home. The number is low: an Ohio nursing home study found 16% legally blind (Kiess et al 1984); a three-year New York City study found 13.9% (Kornzweig et al 1957). Reasons for under-reporting include the scanty information for residents transferred from another facility, residents' embarrassment at acknowledging their poor vision, and even physicians' ignorance of patients' vision (Kallman & Vernon 1937). Also, some residents become blind after entering a nursing home; and because aphasic, confused, bedridden, and/or depressed residents may not alert staff to vision loss, staff may easily overlook that loss.

Information on residents' family, pre-admission residence, tenure at this facility, and medical status were gathered. The key question was not the extent to which residents fit researchers' portrait of depression, apathy, and immobility--but the role of blindness in that portrait.

The variables assess several dimensions of resident well-being.

Residents were judged blind if 1) they were admitted with a diagnosis of "legally blind," 2) they said they could not see or see only shapes, or 3) staff agreed that patient could not see or could see only shapes.



"Other diagnoses" and "hearing" include information that would influence patients' ability to fit into the nursing home community. Conditions cited were those on admission; some conditions, such as a fractured hip or pneumonia, were eventually resolved.

The nursing home functioning questions include:

- 1) self-care independence - ability to dress, wash, and toilet him/herself, all aimed at assessing residents' ability to function independently.
- 2) social interaction - attendance at religious and recreational events, the existence of a friendship with another resident, the practice of eating in a dining room.
- 3) interest in noninstitutional world - the use of telephones, radios, readers and tapes; and
- 4) mobility. The variable denotes the resident's actual means of mobility (walks unassisted, uses cane, uses wheelchair, for instance).

Several items were from Carolan's (1973) study of sensory stimulation in the nursing home.

## Results

Residents divided into two groups: those who were blind before admission to this nursing home, and those who became blind after admission. (Table 1)

"Post-admission" blind are more limited than "pre-admission" blind. The latter were less likely to be dependent for self care, socially isolated, disinterested in the outside world, and immobile--a finding supported by Lukoff & Whiteman's (1972) suggestion that an individual's adjustment to blindness is easier the earlier s/he becomes blind.

In fact, blindness alone did not explain the limited functioning of the pre-admission blind. Six of the ten are dependent on staff for self-care, as

well as socially isolated: they attend no recreational or religious activities, have no friends, and eat in their rooms. Although three of the six

TABLE 1. Comparison of Functioning, Old Blind and New Blind Residents

|  | Old Blind<br>(N=10) | New Blind<br>(N=6) |
|--|---------------------|--------------------|
| Dependent for self care                              | 60% (6)             | 100% (6)           |
| Socially Isolated                                    | 60% (6)             | 83% (5)            |
| No Interest Outside Institution                      | 70% (7)             | 100% (6)           |
| Bed-To-Chair   | 40% (4)             | 66-2/3% (4)        |
| Limited Hearing                                      | 40% (4)             | 17% (1)            |
| Previously Lived in other Nursing Home               | 40% (4)             | 50% (3)            |
| Mental Confusion<br>Schizophrenia/Senile<br>Dementia | 30% (3)             | 0% (0)             |

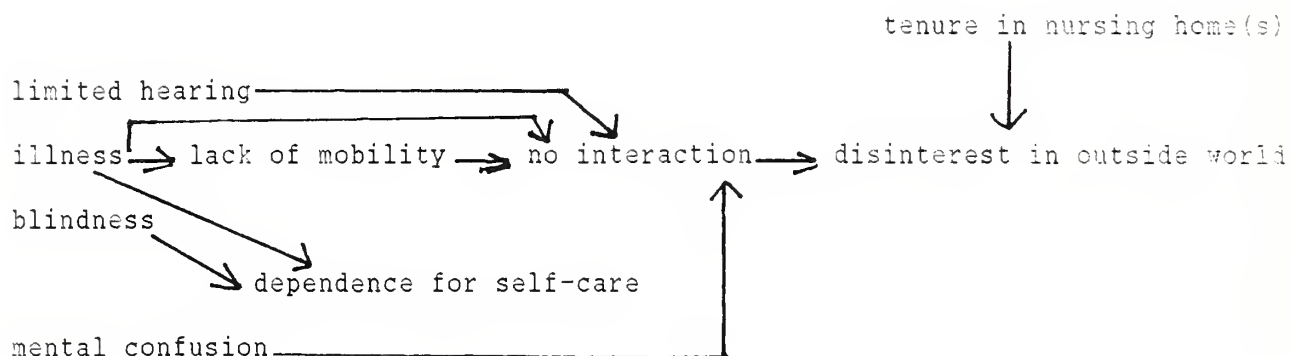
have radios, only one uses tapes; and nobody uses readers or the telephone. At first glance, they fit the model of isolation and dependence. On closer glance, however, their predicament is more complex. The model posits lack of mobility as a key determinant of isolation. Indeed, the four socially involved residents are mobile; yet the converse is not true. All the isolated residents are not bed-to-chair. One resident walks unassisted; another with a person helping.

Indeed, blindness is not their only major disability. Four residents had limited hearing. Four suffered from "schizophrenia" or "senile dementia," admittedly overused terms. Either confusion or deafness would contribute toward social isolation. Two residents were immobile because of an amputation and a stroke. Another patient, with both limited hearing and "senile dementia," had a pelvic restraint when seated. One resident was severely

depressed: she entered the nursing home at age 57, was depressed at her rapid physical deterioration that included a stroke, an amputation, diabetes, as well as blindness. Few residents are interested in the outside world. Only one used tapes, nobody used Talking Books, and two used telephones. Six people had radios, but they can be construed as ubiquitous background noise. These people, however, had lived years at this or other nursing homes. Such veterans may have lost interest in the world outside--a disinterest not directly due to their blindness.

The pre-admission blind residents had learned to cope. Some had participated in the blind community. All had learned about guide canes, Talking Books and tapes, and had lived without sight in a world of the sighted. The nursing home was a new, perhaps frightening environment for them; but blindness did not make them isolated and dependent. Four of the ten participated in the nursing home community and assumed responsibility for self-care. The six who did not had other factors contributing to their isolation.

A more useful model of isolation and dependence would include those other factors.



The six post-admission blind residents fit more closely the originally hypothesized model. Only one had limited hearing; none were confused; yet all

were dependent for self-care. As with the pre-admission blind, these residents' immobility is not due solely to blindness: one had osteoarthritis, and four had had strokes. Except for an occasional radio, none used any linkages to the outside world. Their isolation, however, probably results from their blindness. On entering, most ate in the dining room, attended some recreational activity, and had a friend. Indeed, social work case notes report declining social participation concurrent with declining vision.

### Discussion

Pre-admission blind residents may lead dependent, isolated lives; yet blindness is not central to their quality of life, while post-admission blind residents are newly-disabled. They do not learn about mobility, non-visual senses, and technological aids. They remain dependent, isolated, immobile--not an unusual state in a nursing home population, but not inevitable.

To improve these residents' quality of life, nursing homes need to train staff. Some associations for the blind conduct inservice workshops for nursing home staff (Morrison 1970; Search 1976). Other associations have worked directly with residents although without staff reinforcement of agency efforts, the agency's direct involvement with residents may not be useful (Dinner & Raftary 1984). Staff must learn to feel comfortable with blind people; and, to feel comfortable, staff must first confront their own feelings and prejudices (Greenblatt 1979). Staff must learn simple rules of communication (Rickelman & Blaylock 1983). Staff must encourage mobility and independence, and staff must recognize the dangers in half-opened doors and furniture rearrangements. Some of the training is attitudinal: staff who fear a patient will fall may find it difficult to let a blind person take his arm for a walk. Other training is specific; e.g., you walk with a blind person behind you, at a normal pace (you

do not push or pull the blind person). The very old are at risk for vision loss (Rosenbloom 1982); and although only 13-16% of residents may be legally blind, many others have poor vision. This easily overlooked segment of the nursing home population would benefit from a more knowledgeable, empathic staff.

Blindness researchers have helped children and employable adults live productive lives. Inservice and resident training will not make nursing home residents productive, or even spur their return to the community; but skilled intervention (Culek 1981; Mumma 1975), will improve their lives. Given the long tenure of blind nursing home residents, that goal merits attention.

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OSTEOPOROSIS AS A CHRONIC ILLNESS FOR WOMEN:  
MEDICAL AND FEMINIST SELF-HELP PERSPECTIVE

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Osteoporosis means thin or porous bones that are likely to fracture or, in the case of spinal bone, to become compressed. This condition leads to more than one million fractures each year and one-fourth of all white women between the ages of 60 and 70 can expect to be affected by this bone disorder. Osteoporosis can lead to loss of teeth and wrist fractures in the 50's spinal crush fractures between the ages of 55 and 75 and hip fractures in the 70's and 80's. Women with severe osteoporosis commonly lose three to four inches of height, experience chronic pain, have difficulty walking any distance, become increasingly dependent, and develop a new identity as a chronically ill and disabled person.

Two perspectives on osteoporosis have merged during the past five years - the medical perspective and the feminist perspective. Osteoporosis is being presented to the public by most medical researchers and medical practitioners as a post-menopausal disease. Medical researchers have added osteoporosis to hot flashes, night sweating and vaginal dryness as the major changes that occur after menopause (Cali, 1984). By linking osteoporosis to menopause, lowered estrogen levels are implicated as a prime cause of this condition. Hormone therapy is then presented as a logical and scientific choice for prevention and treatment.

Osteoporosis, from a feminist self-help perspective is basically a condition of aging that is experienced, to some degree, by women and men. The feminist self-help perspective promotes lifelong weight-bearing exercise and a

nutritious diet rich in calcium as the major means for preventing osteoporosis. Women who have already developed osteoporosis are encouraged to join self-help groups.

## THE MEDICAL PERSPECTIVE ON OSTEOPOROSIS

### Estrogen Therapy

As stated earlier, osteoporosis, in the United States, is generally viewed by gynecologists, endocrinologists and medical researchers as a post-menopausal disease. The belief supporting this view is:

Use of estrogen for a minimum of 5-10 years, initiated as soon as possible after menopause, reduces post-menopausal bone loss.

It must be noted that this view stresses a 5-10 year period in the life-span of a woman.

The long-term use of estrogen, however, poses a problem for physicians. In 1975 researchers discovered that unopposed estrogen was linked to an increased rate of endometrial cancer. Currently, progestogen, another hormone, is alternated with estrogen to mimic the menstrual cycle. This is believed to prevent precancerous thickening of the uterine lining.

### Prevention and Treatment

Highly effective, safe methods for treatment of osteoporosis are not available - at best known treatments only slow the loss of bone. Estrogen therapy, although frequently prescribed for treatment, cannot reverse the course of osteoporosis as it cannot help to create new bone.

Since cure is impossible, prevention of osteoporosis is now being emphasized by physicians.

Prevention takes two (2) major forms:

- osteoporosis screening clinics
- hormone replacement therapy.

Screening clinics operated by physicians or hospitals offer non-invasive bone mass measurements. In 1984 there were twenty-five such clinics - there are now more than five hundred in the United States (Napoli, 1986). The costs of these screenings vary from \$40 for a singlephoton absorptionmetry to \$300 for a CT scan. These screenings can show the extent of existing osteoporosis but cannot predict hip fracture. Two types may offer some predictability for vertebral fractures.

Hormone therapy is currently the most common preventive measure used by physicians. Women receiving this therapy become dependent upon physicians for medical exams, uterine biopsies, annual mammograms, and osteoporosis screening.

#### THE FEMINIST SELF-HELP PERSPECTIVE

This perspective has been developed by members of the Women's Health Movement which is one segment of the Women's Movement. Since the 1960's groups of feminists throughout the world have critiqued the sexism, racism, and classism endemic in health care systems. They have created self-help groups, women-controlled health centers and national organizations such as the National Women's Health Network.

Within a feminist self-help framework some degree of osteoporosis is viewed as a natural part of aging for both women and men. There is no clearly defined point, except when fractures occur, when "thin bones" become a problem. Some people with good bone mass fracture and other people with "thin bones" - but strong ligaments and muscles supporting bones - do not fracture. Bone health, in great part, is attained by adequate nutrition and exercise. The belief supporting this view is:

A diet rich in calcium and other nutrients along with ongoing weight-bearing exercise from infancy through old age reduces bone loss.



It must be noted that this belief stresses preventive measures throughout the entire life span of women and men.

### Prevention and Treatment

The feminist self-help perspective "distrusts" osteoporosis screening and hormone replacement therapy except for women at high risk. There are at least 30 biological, medical, lifestyles and socio - political - economic risk factors for osteoporosis. Women with multiple risks may benefit from screening and hormone therapy.

Osteoporosis screening for post - menopausal women can reveal existing bone mass but cannot prevent osteoporosis. A major outcome of this screening could be increased prescribing of hormones. Hormone therapy is suspect due to the damaging histories of diethylstilbesterol and birth control pills. In neither case were these treatments adequately tested in the laboratory before being prescribed for women. The result has been iatrogenic disease: cancer, infertility, strokes. History seems to be repeating itself as the long-term effects of a combination of estrogen and progesterone for older women is unknown.

The feminist self-help perspective emphasizes the value of prevention through offering women counseling at women's health centers, supporting or organizing osteoporosis self-help groups and writing self-help articles. Preventive measures include adequate nutrition, calcium supplements when necessary, and weight-bearing exercise.

The feminist perspective also addresses structural conditions in the United States that make prevention difficult:

- differential incomes between black and white, men and women, young and old that leads to 10 million Americans being undernourished and a dramatic increase in low - birth - weight infants during the Reagan administration.

- widespread unemployment among men contributes to "street violence." People are afraid to walk on the streets to get adequate exercise.
- power of pharmaceutical companies to influence physicians and the media to promote hormones. Medical treatments are commodities and transnational pharmaceutical companies make extremely high profits from the sale of hormones.

### Conclusion

The prevention and treatment of osteoporosis has been analyzed from both a medical and a feminist self-help perspective. Osteoporosis from a medical perspective is a postmenopausal disease to be prevented by hormones. From a feminist self-help perspective osteoporosis is a condition of aging that is experienced, to some degree, by most women and men. It can best be prevented by health policies that ensure an equal distribution of society's resources.

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CHRONIC ILLNESS, COPING RESOURCES AND PSYCHOLOGICAL DISTRESS  
AMONG THE RURAL AND URBAN BLACK ELDERLY

By

|                            |                            |                         |
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There is little question that one's psychological well-being may have a direct influence upon one's physical health and vice versa. The issue of how medical problems relate to psychiatric impairment in large populations is worthy of further study because the pattern of association between mental and physical illness has considerable policy importance in devising strategies to address the needs of the ill population. Further, a deeper understanding of the relationship of medical problems to psychiatric impairment is especially important in rural populations because of the relative scarcity of health and mental health professionals (Hassinger, 1982). Given this shortage of health professionals, if mental and physical disease occur together, they should be diagnosed and treated jointly.

Various studies in urban (Crandell and Dohrenwend, 1967; Husaini, 1983; Langer and Michael, 1963; Leighton, Harding, Hocklin, Macmillan and Leighton, 1963) and rural (Neff, Husaini and McCorkel, 1980; Linn and Husaini, 1985) settings have obtained strong statistical associations between self-reports of physical illness and self-reports of physical impairment. Further, a similar relationship was observed in a study of rural blacks (Husaini and Neff, 1981).

Additional evidence for a direct influence of physical problems, including surgery, thyroid hormone disturbance, and cancer, upon depression



has also been provided by patient studies (Hall, 1983; Hankin, 1980; McGuire, Lee, and Bevington, 1978). The principal objective of this analysis is to examine chronic illness as a risk factor for depressive symptomatology in an understudied population, i.e. elderly (aged 60 and above) blacks residing in rural and urban communities.

The data utilized are drawn from studies of 398 rural West Tennessee blacks interviewed in 1979, and 327 black residents of Nashville, Tennessee interviewed in 1980-82. In both rural and urban samples of black elderly, chronic illness, life event, demographic and personal and social resource covariates of depressive symptoms are explored. In addition, the buffering effects of both social support and personal resources with respect to the effects of chronic illness on depression are analyzed.

Depressive symptoms, which constituted our main dependent measure were assessed with the Center for Epidemiologic Studies Depression Scale (CES-D). This 20-item index taps the presence and frequency of symptoms over the past seven days. Psychometric properties of this scale have been reported by Radloff (1977) and Husaini, Neff, Harrington, Hughes, and Stone (1980). The presence of chronic illnesses was assessed with a chronic medical problems check list derived from the National Health Interview Survey (Wilder, 1973). Respondents were asked to indicate which items on a list of medical problems had been a problem to them during the past year.

## RESULTS

For both rural and urban samples of the black elderly, multiple regression analysis showed that the number of chronic illnesses was the best predictor of depression (the CESD). Life events, our measure of acute stress, produced significant increments in depressive symptoms for

the urban, but not for the rural black elderly. Given the vast literature documenting the effects of life events on depression for a variety of populations including blacks (Aneshensel and Stone, 1982; Markish and Favero, 1974; Pearlin et. al., 1981), it is surprising to find no evidence of a relationship in the rural sample. Possibly, we failed to sample life events for which rural elderly southern blacks would be typically at risk.

The multivariate analyses also showed that low income black elderly in both nonmetropolitan West Tennessee and Metropolitan Nashville were at significantly greater risk for depression. This finding is congruent with recent research (Kessler and Neighbors, 1986; Neighbors, 1986) that shows that low socioeconomic status is related to mental distress in the black population.

Significant buffering effects in both samples of black elderly were obtained for our measure of personal resources (a seven item scale of personal competence developed by Campbell, Converse, Miller, and Stokes, 1960). Elderly blacks with a greater sense of personal control appear to be less vulnerable to the negative psychological effects of chronic disease. However, these findings also suggest an alternative explanation, namely, that people who are depressed because of chronic physical illness also experience low levels of personal competence.

Surprisingly, our measure of social resources (the number of close friends living nearby) does not mediate the effects of chronic illnesses on depression for black elderly living in either rural or urban communities. Perhaps a measure that taps the respondent's perceived quality of their social relations, as opposed to the size of their friendship network, would provide a better test of the hypothesis that a high level of

social support ameliorates the psychiatric effects of chronic physical illness.

Finally, a series of bivariate analyses show that irrespective of their place of residence, elderly blacks with nervous, circulatory, digestive and genitourinary problems are significantly more distressed. Other specific illnesses, i.e. neoplasms and respiratory problems, may have similar psychiatric effects, however we had too few cases to do meaningful tests.

#### CONCLUSION

The results of this analysis show that chronic physical illness is a significant risk factor for depression in the elderly black population residing in rural and urban communities of Tennessee. This is in agreement with the observation of earlier studies done on predominantly white populations that serious physical illness and psychiatric impairment are often found together (see Langer and Michael, 1963; Leighton et. al., 1963; Linn and Husaini, 1985; Neff et. al., 1980).

The findings for the rural black elderly also further substantiate the policy recommendation of Neff and associates (1980) that those who teach nurses and medical students who are planning to practice in rural areas should equip them to do psychiatric screening.

Further, since many of the black elderly are of poverty status with little or no health insurance the observation of Neighbors (1986) applies: "Not knowing if the seeking of professional help will result in further financial hardships may exacerbate the distress low income blacks already feel as a result of their physical condition." This calls for intervention programs that decrease the frequency of economic crises among the poor black elderly and other poverty status individuals.

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